

## Questions and Answers



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

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

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## Introduction

Dying is a part of life, but can be a difficult process. Healthcare agents can make that process easier for patients, their loved ones, and their caregivers. Selecting a health care agent for yourself and agreeing to be an agent for someone you love are among the most important decisions you will ever make. This booklet was written to give you information that will help you make decisions effectively.

There is now clear legal and ethical agreement that patients should have the final authority to make decisions about their own medical treatment. But what happens when patients are too sick to make their decisions known? Every state now has a legal way for people to appoint a health care agent, someone who can be their voice and their advocate if they cannot speak for themselves.

Healthcare agents are vital in this age of spectacular medical advances, because technology enables us to live longer, healthier lives. This technology can create difficult decisions about when to use it near the end of life. Many people want to decide whether or not to undergo life-sustaining treatment if it cannot cure or improve their condition, and can only prolong dying. When most people cannot make their own decisions, they want those decisions made by someone they know and trust, not by medical professionals, administrators, or judges. Appointing a health care agent ensures that your wishes and values guide decisions about your care.

Being the health care agent for someone can be a complex and emotionally wrenching task. These decisions involve deeply-held personal and moral values, as well as legal and medical issues. They are made under difficult circumstances—the death of a loved one—and they can be final decisions. However, being a health care agent can also be rewarding. It is an opportunity to serve and care for someone you love.

Healthcare agents can be extremely beneficial, but only if they are thoughtfully selected and well-prepared to assume the tasks involved. This booklet will provide important information if you are selecting a health care agent or if you are thinking about becoming an agent for someone else. By carefully considering the issues raised in this text, you can reduce uncertainty about what decisions will best reflect your wishes or those of the person for whom you will speak. Careful thought and preparation can even eliminate conflicts among health care professionals, family members, or other loved ones about these complex decisions.



# Appointing a Health Care Agent

## **What is a health care agent?**

A health care agent is someone you designate to make medical decisions for you if you become unable to make decisions yourself. Your health care agent can be a close relative or a personal friend, but should be someone you trust and who knows you well. If you regain the capacity to make decisions, then you, not the health care agent, will have responsibility for making decisions related to your care.

## **Why should I appoint a health care agent?**

When you appoint a health care agent, you are designating a person to 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.

An agent usually is permitted to make decisions in a wide range of medical situations, not just those involving end of life, and can respond to unanticipated events. Decisions can be based not only on what you may have expressed, either verbally or in writing, but also on the knowledge of you as a person. Your agent can consent to treatment and refuse treatment. For example, an agent might consent to a trial of treatment and, if it does not have the expected benefit, authorize its withdrawal. Your agent can take into account other concerns you may have, such as the quality of life that matters to you, your values or religious views, and other personal concerns that might affect your decisions.

In addition, an agent can advocate on your behalf. If a physician is unwilling to honor your wishes, the agent can seek another physician, go to the administrator or ethics committee on your behalf, or take other actions to see that your wishes are respected. Your agent can have access to your medical records and can seek a second opinion for you. Your agent also can see that you receive appropriate pain management and palliative care.

## **How does appointing a health care agent differ from creating a living will?**

A living will is a document that provides specific instructions about end-of-life care.

It may be called a medical directive, declaration, or something else, but its purpose is to give specific directions or guidelines for the care you want to receive. In contrast, a medical power of attorney is a document in which you designate a person to make medical decisions that may or may not be limited to end-of-life care. Generally, the appointment of a health care agent permits more flexible decision making. Living wills, when used without a health care agent, are more limited as a tool for decision making because they cannot address unanticipated medical situations and might be difficult to interpret in a particular circumstance.

## **If I appoint an agent, should I prepare a living will?**

In most states it is not necessary to prepare a living will or other directive if you have appointed a health care agent; however, living wills can still be useful. If the agent must make a difficult decision, the instructions you have given in your living will can reassure your agent that your wishes are being followed. Furthermore, if the person you appointed to be your agent becomes unavailable to speak for you, your living will can provide useful guidance to your caregivers. A thoughtfully prepared living will can be a valuable complement to the appointment of an agent.

## **Whom can I appoint to be my health care agent?**

Your agent can be almost any adult whom you trust to make health care decisions for you. However, most states do not permit you to appoint your attending physician (unless the individual resigns as your physician) or employees of the institution in which you are a patient (unless they are related to you by blood or marriage).

The most important considerations are that the agent be someone:

- you trust
- who knows you well
- who will honor your wishes.

Ideally, it also should be someone who is not afraid to ask questions of health care professionals in order to get the information needed to make decisions. Your agent may need to be assertive and 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 name as your health care agent before you make the appointment.

Some people assume that they should appoint their spouse or adult child to be the agent. This is perfectly acceptable; however, sometimes a spouse or child may not



feel able to make difficult decisions. For example, a husband may say that even if he knew that his wife would not want to be maintained on life-support, he could not make a decision to stop treatment. Or an adult child may not be comfortable dealing with medical issues, raising questions with doctors, or-if necessary-challenging a doctor's authority.

If your close relatives have similar concerns, it can be a relief to them if you appoint a friend or other relative who might be more comfortable with the responsibility. Practical considerations such as location or availability may also influence your choice.

Often people assume that their closest relatives know what they would want, so they think it is unnecessary to discuss preferences with them. However, people sometimes find that when they actually talk with their loved ones about end-of-life issues, they have very different views. Talking openly about the possibilities and your preferences is essential to assuring that your agent knows what you want.

Everyone's situation is unique. Your decision about whom to appoint must be guided by your own circumstances and relationships.

## **Can I appoint more than one person to be my health care agent?**

In many states you may not appoint more than one person to act as your agent at the same time. Unnecessary conflict and confusion may result when one person does not have clear decision making authority. The medical providers also can communicate more effectively when they know that there is one person clearly designated to receive information and make decisions. You can appoint an alternate agent in case the primary agent is unavailable or unable to serve. You can ask your agent to share information and consult with other family members if you wish.

Parents sometimes want to appoint all of their adult children to act together as the agent to avoid "playing favorites." If you do not want to make this choice alone, you could ask your children to decide among themselves who should be the primary agent. Practical considerations such as location often make the decision obvious; sometimes one child

is more willing to take on this role or is more comfortable dealing with medical personnel than another.

## How do I appoint an agent?

Every state now has some legal document to use when appointing a health care agent. Forms are available from a variety of sources that may include your local hospital, department of aging, or department of health. You can also order state-specific documents from National Hospice and Palliative Care Organization at no charge by calling our HelpLine at 800/658-8898

The documents are not difficult to complete, read the instructions carefully and follow the required witnessing procedure. You do not need a lawyer to complete the documents.

Give copies of your completed document to your agent, alternate agent, physician, and anyone else who may be involved with your health care. Keep the original in a safe but accessible place. **DO NOT KEEP YOUR ADVANCE DIRECTIVES IN A SAFE DEPOSIT BOX.** Other people may need access to them. If you wish to change the person you have appointed, you must prepare a new document and be sure to notify and send copies of the new document to all involved. You can change or revoke your appointment at any time.

## Are there limits to the decisions my agent can make?

Yes. Your health care agent cannot make financial decisions or manage your property unless you have provided that authority by other legal means. You can also limit your agent's authority by putting restrictions in your document. In a few states an agent can make decisions based only on what the patient has stated explicitly in the appointment document or living will. You should carefully check the National Hospice and Palliative Care Organization instructions for your state documents and the documents themselves to see what limits apply.

## What should I tell my agent?

Your agent needs to know:

- when and how aggressively you would want life-sustaining treatments applied, if you are terminally ill
- the personal and spiritual values that guide your thinking about death and dying

General statements such as “no heroic measures,” “die with dignity,” or “do everything” can mean very different things to different people and should not be used. To achieve

a clearer understanding between you and your agent you might discuss some concrete situations. The following are some examples:

1. If you suffered a massive stroke or had a head injury from which you were unlikely to regain consciousness, how aggressively would you want to be treated? What if you were conscious but made a poor recovery and were unable to recognize people or to move your body?
2. Would you want life-sustaining treatments that might prolong your life if you suffered from a progressive debilitating disease such as Alzheimer's disease, Parkinson's, or a similar disease and could no longer make decisions? If you want treatments, which ones? Everything? For how long? Indefinitely?
3. If you were in any of these situations, would you want to receive artificial nutrition and fluids by tubes?
4. If you were seriously ill and your heart stopped beating or you stopped breathing, would you want to go through resuscitation attempts or receive long-term mechanical ventilation?
5. If your underlying disease were terminal and irreversible, would you want to receive antibiotics for pneumonia or other infections that might occur?
6. Are there other medical conditions or circumstances when you would never want treatments such as ventilation, artificial nutrition and hydration, or antibiotics? Would you want them on a trial basis? Would you want them regardless of the outcome?
7. If you were seriously ill, would you want aggressive pain management even if it shortened your life?
8. Would you want special attention through receiving palliative care? Palliative care is a comprehensive approach to care that focuses on the physical, psychological and spiritual needs of the patient and the patient's family, maximizing comfort and quality of life.

Although you cannot expect to cover every specific situation that might arise, discussions like this can help your agent understand how you think about the use of medical treatments at the end of life.

## How can I talk about these issues?

Talking about end-of-life issues can be difficult for anyone. One way to approach the subject is to talk about why you have decided to name an agent.

For example:

- Did a particular event cause you to make the decision?
- Did an article you read in the newspaper or something that happened to a family member make you think about it?
- Is the decision part of a broader effort on your part to prepare for the end of life, for instance making your last will and testament for distribution of your property?
- What is motivating you to take these actions now?

Sometimes sharing your personal concerns and values, your spiritual beliefs, or your views about what makes life worth living can be as helpful to your agent as talking about specific treatments and circumstances. For example:

- How important is it to be to be physically independent and to stay in your own home? Independence can be extremely important to some and maybe less important to others.
- What aspects of your life give it the most meaning?
- How important would it be for you to be able to recognize people or interact with them?
- What are your particular concerns about dying? About death?
- How do your religious or spiritual beliefs affect your attitudes toward dying and death? Would you want your agent to take into account the effect of your illness on any other people?
- Should financial concerns enter into decisions about your treatment?
- Would you prefer to die at home if possible?

These are not simple questions and your views may change. It is important that you review these issues with your agent from time to time.

## **How does my agent make decisions?**

Under most states' laws your agent is expected to make decisions based on specific knowledge of your wishes. If your agent does not know what you would want in a particular situation, he or she should try to infer your wishes based on their knowledge of you as a person and on your values related to quality of life in general. If your agent lacks this knowledge, decisions must be in your best interest. Generally, the more confident the agent is the decisions will accurately reflect your wishes, the easier it will be to make them.

In a few states, the law limits the agent's power to refuse some treatments in certain circumstances. State law, for example, may limit decisions to what the patient has specifically stated in the appointing document or in other documents such as a living will. You should carefully review your state documents.

## **What if I know that members of my family disagree with my wishes?**

To ensure that your wishes are followed, be certain that the person you appoint to be your agent understands your wishes and will abide by them. Your agent has the legal right to make decisions for you even if close family members disagree. However, should close family members express strong disagreement, your agent and your health care professional may find it extremely difficult to carry out the decisions you would want.

- If you foresee that your agent may encounter serious resistance, the following steps can help: communicate with family members you anticipate may object to your decisions. Tell them in writing whom you have appointed to be your health care agent and explain why you have done so.
- Let them know that you do not wish for them to be involved with decisions about your medical care and give a copy of these communications to your agent as well.
- Give your primary care physician, if you have one, copies of written communications you have made.

- Prepare a specific, written living will.
- Make it clear in your documents that you want your agent to resolve any uncertainties that could arise when interpreting the living will. A way to say this is: “My agent should make any decisions about how to interpret or when to apply my living will.”

## Conclusion

Appointing someone you trust to be your health care agent is an important step toward assuring that if you are not able to make decisions for yourself, your preferences for medical treatment will be carried out at the end of your life. You should complete the document appointing your agent carefully and follow the witnessing requirements in your state. Take time to talk openly with your agent so that he or she is fully aware of your values and your wishes about end-of-life care. Also, take time to talk with other loved ones and health care professionals, so they understand your wishes and reasoning. Many people will consider being asked to serve as a health care agent an honor as well as a responsibility. You can return your agent’s gift to you by providing her or him with as much preparation as you can.



## Being a Health Care Agent

### Why would I want to be a health care agent?

Accepting the appointment to be a health care agent is a way of affirming the importance of your relationship to the person appointing you. However, accepting an appointment requires thoughtful consideration about whether you can fulfill the role appropriately. Acting as a health care agent brings significant responsibilities and should be viewed as an honor to be given such trust.

There also are practical reasons for accepting formal appointment as an agent. If you are the closest relative to the patient, you can expect to be the person that health care professionals will look to for consent or decisions if the patient cannot make them. However, some state laws limit this informal decision-making process, particularly in cases of decisions to forgo or withdraw treatment. Without a formal appointment you may be able to consent to treatment but not refuse it or have it stopped, even if you know it is unwanted. To stand by helplessly watching someone you love be treated in a way you know that person would not have wanted can be a very painful experience.

If there is a conflict among family members and no agent has been designated, medical providers will normally continue all treatment until the conflict is resolved. Even if you are the person who knows the patient best and the one in whom the patient has confided, you may be unable to speak for the patient unless you are the legally designated agent. You may be excluded from decisions, particularly if you are not a close relative. It is not uncommon today for a friend to be closer to a person than family members who may live far away. If you are a formally-appointed health care agent, your authority has priority over all others, including family members.

## **What are my responsibilities as a health care agent?**

As the health care agent you have the power to make medical decisions if the patient loses the capacity to make them. Unless your authority to act is limited by the patient or the state law, you normally can make all medical decisions for the patient, not only end-of-life decisions. In most states, as the health care agent you can also speak for the patient even if he or she becomes temporarily incapacitated as might occur after an accident. Generally, you may speak for the patient only as long as the patient is unable to make decisions.

You need to read the state forms and the instructions carefully to find out if there are any limitations upon your authority to make health care decisions. For example, in a few states your authority to make end-of-life decisions is limited to circumstances addressed in the document. Some limit the agent's ability to make decisions related to psychiatric hospitalization or shock treatment. A few states require that the agent have some specific knowledge about the patient's wishes regarding artificial nutrition and hydration or other specific treatments.

One of an agent's most important functions is as an advocate for the patient. Advocacy can involve asking to see medical records, meeting with the physician to get information about the patient's diagnosis (what is wrong with the patient) and prognosis (what is the likely outcome of this medical condition, with treatment and without treatment), and getting other information that is needed to make decisions about treatment.

Physicians do not always understand the authority of an agent. Although most physicians understand that patients are entitled to information, they may not realize that the agent is entitled to the same information that the patient could receive. Therefore, as the agent you may need to be assertive and persistent in seeking information and in speaking up on the patient's behalf.

However, if you are respectful but firm, you should be successful in having your authority recognized. It is important for you to remember that you have the legal authority to speak for the patient, not the physician, nurses or other health care professionals.

There are others who can be helpful to you. There may be a patient representative, nurse, or social worker who can help you advocate for the patient. In addition, outside organizations such as the National Hospice and Palliative Care Organization can provide valuable information and advice. In the back of this booklet, you will find resources that also can be useful.

## **How do I make decisions as a health care agent?**

Generally, you will be required, as far as possible, to make the same medical decisions that the patient would have made. To do this you might need to examine any specific statements that the patient made (either orally or in writing, such as in a living will), as well as consider the patient's beliefs and values. If you have no information about what the patient would want, you must act in what you believe would be in the patient's best interest, using your own judgment. To arrive at that decision, you might ask the patient's doctors what kind of benefits and burdens might result from the treatment; you can draw on knowledge that others have about the patient and on their opinions; or you can ask others what they would want if they were in such a situation. However, the more you and the patient have talked, the less likely you will be in the dark about what the patient would want.

## **When would I be asked to make decisions?**

Normally the agent becomes the decision maker after the attending physician determines that the patient either temporarily or permanently lacks the ability to make health care decisions. Many states also require that a second physician confirm the patient's incapacity if the decision involves withholding or withdrawing life support treatments.

## **What do I need to know to make decisions?**

You need to gather as much information as possible about the patient's condition. What is wrong with the patient (the diagnosis)? What is likely to happen to the patient because of the disease or medical condition (the prognosis)? If the doctors are unsure of the diagnosis or prognosis, you need to know when they will know more and what they are doing to get more information.



Sometimes the process of obtaining information involves invasive and uncomfortable testing, and you will need to decide if the process should go forward. For example, you may know that the patient would not have wanted invasive testing, or you may decide that the burdens of testing and or treatment outweigh any likely benefits.

Therefore, information about the patient's prognosis is particularly important. What, given the present situation, is the most likely outcome? Although the outcome may never be known absolutely, you can ask what chance the patient has to return to his or her previous condition, or if that is not realistic, what is the best outcome that could be expected? The worst?

If the doctor says the patient may improve with treatment, what does "improve" mean? To a doctor "improve" might mean survival, but with serious brain damage. You may know that the patient would not want treatment if that was the most likely outcome. If the doctor says that the patient has a treatable condition, such as pneumonia, but this treatment cannot affect the underlying disease, such as advanced Alzheimer's disease, you may know that the patient would not want life prolonged under these circumstances. Or you might decide that because of other aspects of the patient's condition (for example, advanced cancer), further treatment would only prolong the patient's dying in an uncomfortable or painful condition. It could be an appropriate decision to refrain from treating the pneumonia and concentrate only on treatments that would keep the patient comfortable. (Such treatments are commonly called palliative care.)

You also can ask the physician to describe how the patient's disease is likely to progress and what decisions are likely to be necessary at some point. For example, a patient with Alzheimer's disease eventually might stop eating or become unable to swallow. You can begin to consider whether artificial nutrition and hydration should be given if that happens, and obtain specific information about these treatments. If someone is very sick, it is likely that at some point they will have cardiac or pulmonary arrest (their heart will stop beating or they will stop breathing). Start talking with the doctor early about whether or not a do-not-resuscitate (DNR) order should be written to prevent the use of cardiopulmonary resuscitation (CPR).

In discussing whether to withhold or withdraw particular treatments, you should also ask the physician about the care that the patient would continue to receive. You should expect a palliative care plan to be in place to manage any pain or discomfort. You can consider non-hospital options for the patient's care. For example, appropriate care might be delivered more effectively in a long-term care facility or it could be given at home with home-care support or hospice care.

If you need information from the doctor, ask for an appointment to meet and come prepared with specific questions. Write your questions down so that you do not forget any of them and you can make good use of the time. You can get information and other support from nurses, social workers, patient representatives, members of the ethics committee, and chaplains. The National Hospice and Palliative Care Organization also offers publications that discuss various treatments and end-of-life decision making issues through its Marketplace Catalog at [www.caringinfo.org](http://www.caringinfo.org).

Medical decision-making is a process. You can make provisional decisions and change them later. For example, you can authorize a trial of treatment, and later, if the treatment is not having the intended benefit, direct that it be stopped. It is perfectly ethical and legal to stop a treatment that has been started if the treatment is of little or no benefit or is unwanted.

However, in practice, withdrawing a treatment can be psychologically more difficult for the caregivers and the agent. It can feel as if stopping the treatment causes the patient's death. In fact, the treatment may only prolong the dying process, rather than prevent the patient's eventual death or improve the patient's condition. In such a situation it can help to remember that the disease is the real cause of the patient's death, not stopping or withholding treatment. Sometimes withholding or withdrawing treatment does not result in the patient's immediate death, but may make the patient's dying more comfortable.

Take the time you need to get the information that you feel is necessary to make a thoughtful decision. There may be no "right" decision. You can only make the best decision that you can under the circumstances.

## **What if the doctor refuses to follow my directions?**

In most states care providers can refuse to honor advance directives (directives communicated by the agent or a living will) for moral or religious reasons. Some of those states require that care providers remove themselves from the case and transfer care of the patient to someone who will honor the patient's request. But in practice, a health care professional's refusal to honor an advance directive can cause a new set of issues. For example, it may be difficult to arrange the patient's transfer to another physician or facility.

A refusal to stop treatment that stems from a misunderstanding of the law or medical ethics might be resolved by supplying the provider with the correct information. In

other instances a care provider may feel that the patient's choice conflicts with his or her professional responsibilities or personal moral values. Many medical facilities have ethics committees that might help to resolve disputes over patients' wishes. In extreme cases legal action may be required.

A possible way to avoid such conflicts is to speak about the patient's wishes with the physician when you discuss other issues related to the patient's condition or treatment. This discussion will give you an opportunity to find out something about the physician's perspective and values related to end-of-life decision making. If the physician is unresponsive when issues about patient's treatment wishes are raised, or expresses an unwillingness to honor the patient's wishes, you may want to transfer the patient to someone else's care before a conflict arises.

### **If I withdraw as the agent, can anyone else make decisions for the patient?**

If the patient has appointed an alternate agent, you can withdraw and the alternate agent will become the legal decision maker. If there is no appointed alternate agent, the outcome varies among the states.

In some states, law sets forth a procedure for making decisions for patients who do not have designated decision makers. The law usually designates someone from a ranked order of those who can make decisions, for example, the legal guardian, spouse, majority of adult children, and so forth. However, in some states there is no provision for decision making in the absence of an appointed agent unless the patient's own wishes are clearly known. If the patient's wishes are not known, treatment may have to continue.

### **How should I handle my personal feelings when acting as a health care agent?**

It is very important that you stay in touch with your own feelings while you are acting as an agent. Otherwise, you may not realize that they can affect your behavior and even your decisions. You may be experiencing anxiety or fear about what will happen to this person you love. You may be concerned that the person is suffering or is in pain and may worry about how treatment will affect his or her condition. You may fear that you will not do the right thing or that you are not being assertive enough. You may worry that you are making decisions that make you feel better rather than those that are best for the patient. You may also be struggling with grief, particularly if the disease has taken away the person you knew or if you anticipate that the

person will soon die. Sometimes people feel guilty for having withheld or withdrawn treatment, even when they know for certain that doing so is what the patient wanted. It may help to remember that if it were not for you, the person you love might have had to endure a treatment that they did not want, or they might have been deprived of care that they did want.

It is hard to listen and to hear what health care professionals are saying when you are under emotional stress. It is difficult to be objective when you are afraid of losing someone you love. End-of-life decisions can be particularly difficult even when you know the person's wishes very clearly. Try to accept your feelings and be patient with yourself. You can usually defer making a decision until you have a chance to think about it. Do not blame yourself if you forget to ask something or if you are afraid you made a wrong decision. If, after thinking things over, you want to change your mind, you generally can do so. As a rule, you can find another opportunity to ask questions.

Unacknowledged feelings can make you very angry, and your anger may come out in inappropriate ways such as arguing with doctors, nurses, and others caring for the patient or with family members. Creating conflict when it is unnecessary will make it more difficult for you to get information and be an effective advocate. Anger can even hurt the care of the patient if the focus of those caring for the patient shifts from dealing with the patient's needs to dealing with you.

It is perfectly appropriate to seek help. People without medical experience cannot be expected to understand the health care systems and the medical issues that are involved. You should expect to need guidance in dealing with them. Some physicians can be quite sympathetic to the issues you are dealing with and, if asked, will try to help. If you feel particularly comfortable with a nurse, talk with him or her. Chaplains often have a great deal of experience dealing with individuals and families struggling with difficult decisions and can be very helpful, even if you do not share a common religious outlook. Patient representatives and social workers also may be resources. Look to your own friends and communities. Sometimes people you do not know well, but who have gone through similar situations, can be a wealth of support and information.

## **Conclusion**

Serving as a health care agent is both an honor and a responsibility. You have probably been asked to serve because you have a personal and emotional connection to the person making the appointment. The person trusts you and believes you can use your best judgment. There is no ideal standard for the perfect agent. You can only

do the best job that you can do. This booklet highlights some of the challenges an agent may face and offers suggestions for possible responses; however, the situations covered here may never occur or you may encounter different ones. If you are called upon to act as a health care agent, it may help to bear in mind that you are providing a deeply-needed service to someone who is now helpless. This knowledge can be a source of great personal comfort and satisfaction for you and can sustain you when making difficult decisions.

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](mailto:consumers@nhpco.org) or visit our Web site at [www.caringinfo.org](http://www.caringinfo.org) where you will find a variety of resources and information and can order publications.

### **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 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 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 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 condition and goals for care.

### **Capacity**

The ability to understand the nature and consequences of health care decisions.

### **Cardiac Arrest**

An event in which the heart stops beating, causing all body functions to shut down, including breathing.

### **Cardiopulmonary Resuscitation (CPR)**

CPR is the medical treatment used by health care providers to restart the heart and/or restore the breathing of someone who suffers a cardiac or respiratory arrest. CPR

involves a group of procedures that may include artificial respiration and intubation to support or restore breathing, and chest compression or the use of electric stimulation or medication to support or restore heart function.

### **Do-Not-Intubate (DNI) order**

A physician's written instructions to health care providers not to intubate (see "intubation" below) a patient who is experiencing breathing difficulties.

### **Do-Not-Resuscitate (DNR) order**

A physician's written instructions to health care providers not to perform CPR if a person experiences cardiac or respiratory arrest.

### **Emergency Medical Services (EMS)**

A group of governmental and private agencies that provide emergency care, usually to people outside of health care facilities; EMS personnel generally include paramedics, first responders and other ambulance crews.

### **Healthcare Agent**

The person named in an advance directive or as permitted under state law to make health care decisions on behalf a person who is no longer able to make medical decisions.

### **Hospice Care**

A program to deliver palliative care to individuals who are in the final states of a 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 grief support for up to one year after the patient's death.

### **Intubation**

Refers to "endotracheal intubation" the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

### **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 CPR, mechanical ventilation, artificial nutrition and hydration, dialysis, and other treatments.

### **Living Will**

A document that allows individuals to record instructions about their medical treatment in the event they become terminally or irreversibly ill and unable to communicate.

**Medical Power of Attorney**

A document that allows individuals to appoint a trusted friend or family member to make medical decisions on their behalf in the event they become unable to communicate.

**Non-hospital DNR Order**

A physician's order that directs emergency medical providers and other health care workers not to attempt CPR for persons being cared for at home. Laws and regulations governing their use vary from state to state.

**Respiratory Arrest**

The cessation of breathing—an event in which an individual stops breathing. If breathing is not restored, an individual's heart eventually will stop beating, resulting in cardiac arrest.

**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” or “hospice-type care.”



## Publications

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

**NHPCO Catalog Number 715112**

*Choices at the End of Life: Finding Out What Your Parents Want Before It's Too Late* by Linda Norlander, Kerstin McSteen. Helps readers to develop a living will/advance directive, avoid family disputes over medical treatments, and presents a comfortable way to have an advance talk with parents about preferences for end-of-life health care.

**NHPCO Catalog Number: 820373**

*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](http://www.caringinfo.org).

## Organizations

### AIDS Hotline

800/342-AIDS (2437) or 800/227-8922

Operated by the Center for Disease Control and Prevention, AIDS provides general information about AIDS, HIV, and sexually transmitted diseases (STD's), as well as referrals to HN 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

800/782-4747

27001 Agoura Road, Suite 150

Calabasas Hills, CA 91301-5104

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

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

### Alzheimer's Disease and Related Disorders Association

800/272-3900

919 North Michigan Avenue, Suite 1100

Chicago, IL 60611

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

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

### **American Association of Retired Persons (AARP)**

800/424-3410 or 202/434-2277

601 East Street, NW

Washington, DC 20049

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

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

### **American Chronic Pain Association**

800/533-3231

PO Box 850

Rodding, CA 95677

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

Provides peer support and coping skills to anyone with chronic pain.

### **American Society of Aging**

800/537-9728

833 Market Street, Suite 511

San Francisco, CA 94103

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

Provides education and training resources for professionals working in the field of aging.

### **Cancer Care, Inc.**

800/813-HOPE (4673)

275 7th Avenue

New York, NY 10001

[www.cancercare.org](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. Includes resource information for caregivers.

### **Cancer Information Services** (*National Cancer Institute*)

800/4 Cancer (422-6237)

[www.cancer.gov](http://www.cancer.gov)

Answers questions related to cancer and cancer treatment. Provides referrals to hospice, home care and support groups.

### **Caring Connections**

[www.caringinfo.org](http://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.

### **Genetic Alliance: Help Line**

800/336-GENE (4363) or 202/966-5557 (Open 9–5 EST)

4301 Connecticut Avenue, NW, Suite 404

Washington, DC 20008

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

An international coalition of individuals, professionals and genetic support organizations working together to enhance the lives of everyone impacted by genetic conditions. Information on support groups.

### **Hospicelink** (*Hospice Education Institute*)

800/331-1620

190 Westbrook Road

Essex, CT 06426-1510

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

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

### **Medicare Rights Center Hotline**

800/333-4114

1460 Broadway, 11th Floor

New York, NY 10036

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

Provides telephone hotline services to people with Medicare questions or problems. Provide education materials about Medicare benefits and rights.

### **National Alliance for Caregiving**

301/718-8444

4720 Montgomery Lane, 5th Floor

Bethesda, MD 20814

*[www.caregiving.org](http://www.caregiving.org)*

Provides resources and support for family caregivers and the professionals who serve them. The Web site features the review and evaluation of a large number of resources available for caregivers.

### **The National Hospice and Palliative Care Organization (NHPCO)**

800/658-8898

1700 Diagonal Road, Suite 625

Alexandria, VA 22314

*[www.nhpco.org](http://www.nhpco.org)*

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

### **Visiting Nurses Association of America**

888/866-8773 x221 or 617/523-4042 x221 (9 AM–5 PM EST)

99 Summer Street

Boston, MA 02110

*[www.vnaa.org](http://www.vnaa.org)*

Provides information about the nearest visiting nurse agency in their area. Visiting Nurse Association services include: nursing, physical, occupational, and speech therapy, medical social services, high-tech home interventions, case management, personal care, adult day care, respite care, hospice, nutritional counseling and meals on wheels.

### **United Network for Organ Sharing**

888/894-6361 (Monday–Friday, 9 AM–5 PM EST)

700 North 4th Street

Richmond, VA 23219

*[www.unos.org](http://www.unos.org)*

Provides information about how to become an organ donor, how the organ donation network works and other national resources relating to organ donation.

## **Additional Web Resources**

### **Association of Cancer Online Resources**

*[www.acor.org](http://www.acor.org)*

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

### **Caregiver Survival Resources**

*[www.caregiver.com](http://www.caregiver.com)*

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

### **Family Caregiving 101**

*[Familycaregiving101.org](http://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](http://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 illness and end-of-life issues.”

### **National Association for Home Care**

*[www.nahc.org](http://www.nahc.org)*

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

### **The Mayday Pain Project**

*[www.painandhealth.org](http://www.painandhealth.org)*

This web site provides a guide and index of Internet information to those in pain. This site is targeted to care givers, 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**



*For more information contact:*

**The National Hospice and Palliative Care Organization**

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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