

Hospice Information

from the California Hospice Foundation Website

http://hospicefoundation.info/hospice_information.htm

What is hospice?

Hospice is a form of health care that is provided to people who are confronting a fatal illness and for whom curing the disease is no longer a realistic goal.

Hospice provides an all-inclusive set of services needed to manage all of a person's symptoms and complications. It can be provided to people facing a variety of diseases such as cancer, end-stage heart disease, dementia and lung disease, among others.

By providing pain and symptom management, as well as emotional and spiritual support for the individual and family, hospice helps people to live as fully as possible, in comfort and with dignity. The exact services and resources that someone needs are tailored to the needs of the individual and family, based on an assessment of an interdisciplinary team that includes a physician, nurses and social workers. The same team – along with spiritual counselors, home health aides, therapists, and volunteers – ensures that services and resources are provided when needed, without the family having to locate and arrange for them.

How hospice works

Hospice services are available to persons who can no longer benefit from curative treatment; the typical hospice patient has a life expectancy of six months or less. Most receive care at home. Services are provided by a team of trained professionals -- physicians, nurses, counselors, therapists, social workers, aides and volunteers -- who provide medical care and support services not only to the patient, but to the patient's family and loved ones.

How hospice is different

- Hospice offers palliative, rather than curative treatment.
- Under the direction of a physician, hospice uses sophisticated methods of pain and symptom control that enable the patient to live as fully and comfortably as possible.
- Hospice treats the person, not the disease.
- The interdisciplinary hospice team is made up of professionals who address the medical, emotional, psychological, and spiritual needs of the patient and loved ones.
- Hospice emphasizes quality, rather than length of life.
- Hospice neither hastens nor postpones death, affirms life and regards dying as a normal process.
- Hospice considers the entire family, not just the patient, the "unit of care."
- Patients and their loved ones are included in the decision-making process, and bereavement counseling is provided to the family after the death of their loved one.
- Hospice offers help and support to the patient and family on a 24-hour-a-day, seven-days-a-week basis.
- For hospice patients and their loved ones, help is just a phone call away.

Who pays for hospice care?

Hospice is covered by Medicare and most commercial insurance. It pays for a wide range of support services that are aimed at keeping someone as comfortable as possible – including medications, medical equipment, supplies, home assistance (such as for bathing), therapists, and respite care. While each hospice has its own policies concerning payment for care, it is a

principle of hospice to offer services based upon need, rather than the ability to pay. While hospice care is a covered benefit under many insurance plans, hospices also rely heavily, if not entirely, upon community support for donations to provide care to those who cannot otherwise afford it.

FAQs about hospice

The following are some basic answers to frequently asked questions about a hospice program of care. Additional information about hospice is available from the California Hospice and Palliative Care Association or from a hospice in your area.

- **What is hospice?** Hospice is a form of health care that is provided to people who are confronting a serious illness when curing the disease is no longer a realistic goal. It includes all of the services needed to manage someone's symptoms and complications. By providing pain and symptom management, and emotional and spiritual support for the whole family, hospice helps people to be comfortable and retain their dignity.
- **Are there different types of hospice programs?** Hospice programs differ in size, scope of care, and organization. Programs may range from volunteer hospices that rely heavily on professional and lay volunteers, to organizations that provide comprehensive palliative and support services through employees and lay volunteers.
- **When and how are hospice referrals made?** Hospice care is available to terminally-ill patients who no longer wish treatment to cure their disease and who have a limited life expectancy (6 months or less). Although the patient's primary physician usually refers to hospice, referrals can also be made by family members, friends, clergy, or health professionals.
- **Is hospice just for people with cancer?** No. Hospice care can be provided to people with end-stage heart disease, dementia, and lung disease, in addition to cancer and other diseases. The focus of hospice is to support the best quality of life that is possible, not only for the person who is ill, but for his or her loved ones.
- **What services are covered?** Hospice nurses evaluate what the person and family need in terms of physical, emotional and spiritual support and coordinate care with a physician and a team of health professionals. These services are usually covered by Medicare and other commercial insurance. Family members can also receive bereavement support for up to one year. Besides the support services, the patient's primary physician can continue to bill Medicare under its Part B benefit.
- **What isn't covered?** Hospice insurers, including Medicare, don't pay for a round-the-clock home nursing, although they may cover a limited amount. Family and friends are the primary caregivers, with 24-hour access to health professionals who are on call to help manage a patient's symptoms and support the family. Because hospice is aimed at palliative (comfort) care, it also does not pay for clinical trials or other medical services aimed at cure.
- **What if someone changes their mind and wants to go back to curative treatment?** They can leave the hospice program. Later, if the person wants to return to hospice, and still meets program criteria of a six month life expectancy, they can return.
- **Where is hospice care provided?** Hospice care is most often provided at home, but it can also be provided to someone who is in a skilled nursing or assisted living facility. Although less common in California than in some other regions, there also are some facilities that are dedicated to hospice care.
- **When is it appropriate to ask about hospice? How does it begin?** You don't have to wait until a physician brings up hospice to ask about it. The best time to learn about hospice and ask questions is before such services might be needed. Hospice care is available to people who are expected to live six months or less, no longer wish to pursue

a cure and want to receive hospice care. Hospice care begins with a referral – usually from someone’s primary physician – but referrals can also be suggested by family members, friends, faith leaders, or health professionals. Hospice usually begins within 48 hours after a referral, but services may start faster in an urgent situation. For example, if someone is in a hospital, hospice care may be arranged to start upon discharge from the hospital.

- **Does someone give up their physician if they choose hospice care?** Choosing hospice does not mean that someone has to give up their relationship with their physician. Some families become very involved with the hospice teams that support them, which include a medical director who has extensive experience in pain management. Personal physicians can remain involved and informed and can bill for their professional services.
- **What kind of health care professionals provide hospice care?** Hospice programs are known for their coordinated teams that draw upon many different kinds of professionals to ensure that services and resources are provided when needed, without the family having to locate and arrange for them. The interdisciplinary team includes a physician, nurses, and social workers – along with spiritual counselors, home health aides, therapists, and volunteers. The team develops a plan of care, teaches the family caregivers how to provide care, advocates for the patient and family, and provides bereavement support in addition to managing changing symptoms.
- **What is a hospice plan of care?** The plan of care is an outline of the care the hospice interdisciplinary team perceives as necessary to meet the needs of patients and families. It contains the plan the team develops to manage the patient's pain and symptoms, and also outlines plans for meeting the psychological, social and spiritual needs of the patient and family.
- **Are family members involved in hospice care?** Hospice views the patient and family as a unit of care. Family members and friends are encouraged to participate in the patient's care as much as possible. When family members cannot provide as much care as may be needed at certain times, hospice personnel will try to meet the patient's needs by exploring other options.
- **What if someone doesn't have family who can serve as caregivers?** Hospice programs may be able to help identify friends and people in the community who volunteer to help. All hospice programs have a group of volunteers who have been trained to support terminally-ill people and their families. They may provide companionship, emotional support, prepare light meals, run errands, or undertake other tasks to help.
- **Does the patient's primary physician work with the hospice team?** The patient's personal physician often refers the patient to the hospice program and usually either continues to plan most of the patient's care or works in coordination with the hospice team.

Choosing a hospice

There are over 3,000 hospices in the United States, and they vary widely in size, organization and scope of services. In some communities there may be several competing hospices from which to choose. Other health care providers may also offer "hospice-like" services for the dying, but consumers should be aware that they do not have to meet the same requirements or standards or have the same level of expertise as a true hospice.

Questions to ask a hospice

The following are a number of questions that thoughtful consumers can ask when trying to choose the right hospice program for themselves or their loved ones:

1. What are the hospice's admission policies and procedures? How well do these fit your unique needs?
2. From the very first phone call, does the agency project an attitude that is patient, caring, competent and confidence-inspiring? Or do you hear a lot of jargon and conditions and restrictions?
3. If you are uncertain about whether hospice is right for you, what kinds of consultation or assessment will the agency offer to help sort out your uncertainty?
4. How quickly can the hospice initiate services?
5. What are the geographical boundaries or other limits to its services?
6. What are its policies on inpatient care and where is the inpatient care provided, if this should become necessary? How long can patients stay there? Can you tour the unit? Does the hospice contract with local nursing homes? Which ones?
7. Is participation in the care by a family caregiver required as a condition of hospice enrollment? What is expected from the family caregiver, and what can the hospice offer to supplement the family's responsibilities?
8. What is the hospice's past relationship with your personal physician? Can they work together effectively? Does the hospice medical director make home visits, when needed?
9. Who provides on-call coverage? What is the average wait to get your call answered when you have an after-hours emergency, and how quickly can a nurse come to your home, if that is needed? A hospice that uses an answering machine to respond to crises may not inspire much confidence.
10. How often do the nurse, social worker and aide visit typically, and for how long each time? Is it usually the same person? What is the average caseload managed by each nurse?
11. How does the hospice define "palliative" treatments? Are certain treatments automatically excluded? If you require expensive high-technology therapies or devices to manage pain and other symptoms, will this be an issue?
12. What out-of-pocket expenses should you expect?

The questions above are adapted with permission from "The Hospice Handbook: A Complete Guide," by Larry Beresford, published in 1993 by Little, Brown & Co. This book is still in print and can be ordered through most bookstores.

FAQs about advance health care directives

- **What is an advance directive?** An advance health care directive is a written expression of what a person does and doesn't want if he or she becomes ill and can't communicate or make decisions.
- **Where can I get an advance health care directive form?** You don't have to use a special form as long as it meets legal requirements in the state where you live. For the form to be legal in California, it requires a signature, date and two witnesses (plus special requirements for residents of skilled nursing facilities). If you choose to use a form, they are available at no cost from many sources, including physicians and hospitals, insurance plans and from the Internet. The California Hospice Foundation is also a good source. If you visit another state often or move, make sure your form is legal there.
- **When should I complete an advance health care directive form?** There's no time like the present. You don't have to wait until you're facing a medical procedure or hospitalization; in fact, it is far better to talk about your preferences when you are well so that you and others are not under pressure.

- **I already have an advance directive, but I don't know how to talk to someone close to me about their wishes. What should I do?** You may worry that you will be seen as morbid or intrusive if you raise end-of-life wishes to others. You can tell them you want to make sure they get what they want at a critical time, and to avoid misunderstanding within the family. Telling someone why it is meaningful to you allows the family member to approach the topic from a perspective that may be more comfortable. Offering your loved one help to express their needs and preferences can be a profoundly loving act.
- **Do I need an attorney to complete an advance health care directive?** No. Any type of form is legal in California as long as it has your signature, date and the signature of two qualified witnesses. If you live in a skilled nursing facility in California, there are special witnessing requirements including the signature of the patient advocate or ombudsman. You might want to consult an attorney if you live for part of the year out of state or you have concerns.
- **Is it enough to complete an advance health care directive form?** Besides completing a form, it is most important to talk to those closest to you about your wishes, as well as your physician. Forms also allow you to name someone who can advocate for your wishes if you become unable to communicate them yourself -- a "health care agent" (sometimes called a "proxy"). Many individuals also sign a "health care power of attorney" so that their agent can make health care decisions and see medical records if needed.
- **Talking about the possibility of death makes me and others uncomfortable. Why should I do this?** Letting those closest to you know your wishes, or helping others to express theirs, is one of the most loving acts a person can perform. Family discussions and advance directives:
 1. Provide direction, clarity, and purpose for family and caregivers
 2. Allow family and caregivers to offer support with greater peace of mind and a clearer sense of purpose because they understand better what is desired
 3. Reduce one's own fear by creating confidence that care will be tailored to one's preferences
- **What kinds of things should I consider when I express my wishes?** There are four main topics to consider in preparing end-of-life directives: comfort and personal treatment, medical treatment, remembrance, and who will speak for an individual facing a life-threatening situation. A helpful checklist and discussion guide can be downloaded from the California Hospice Foundation website.
- **How do I choose a health care agent to speak for me? Do I have to appoint a health care agent?** You don't have to appoint a health care agent, but it can be very comforting to know that someone you trust can speak for you if needed. The person you choose should be someone who understands your wishes and in whom you have confidence. Consider who will be most able to carry out your wishes in an emotional situation and who will be able to deal with the health care system. It's also a good idea to identify an alternate.
- **Do I have to have a written form to make my wishes legal?** No. Oral instructions to your family or physician are just as legal as written ones. You should know that oral instructions only apply to the duration of your stay in a health care facility. Keep in mind, however, that many disputes arise because a health care agent, physician, and family have different interpretations of oral instructions. Physicians are required to note any instructions that you give them in your medical record. The clearer you are about your wishes, and the more you reinforce them in writing, the more likely that disagreements will be avoided.