Understanding Hospice

What is hospice care?
Hospice care is for patients who are nearing the end of life. When cure is no longer possible, hospice gives patients comfort care in the last phase of their lives. Hospice helps patients live as full a life as they can while honoring their wishes for a peaceful death. Research shows that hospice care may improve:

- A patient's physical symptoms and emotional well being.
- Family and caregiver well-being.
- Family and caregivers' ability to come to terms with the loss of a loved one.
- Patient and family satisfaction.

Hospice helps patients by treating pain and symptoms. It also gives emotional and spiritual support. Hospice lets the family, including children, spend more time with their loved one. This helps them accept their loved one's terminal illness. Hospice also supports the needs of family, friends and loved ones, especially those who care for the patient at home.

You may think hospice is only for patients with cancer, but hospice is for patients with any disease that can cause death. For example, patients may get hospice care because of end-stage dementia, heart disease, lung disease, stroke or kidney disease.

How do you enroll in hospice?
Anyone can refer a patient to hospice. It could be the patient, family caregiver, doctor or nurse. Talk to your doctor if you want to know more about hospice. Find out if the time is right. This can be a hard topic to discuss. Some doctors may hesitate to bring it up. They will welcome patients or loved ones raising the issue.

To get hospice care patients must:

- Have a life expectancy of six months or less if the disease follows its natural course.
- Be ready to stop aggressive, cure-seeking treatments.
- Be approved by their main doctors and hospice medical directors.
- Agree to hospice services.

Patients may get hospice care for longer than six months if they still have a terminal disease and their doctors approve.

Where does hospice take place?
Hospice care occurs at the place the patient calls home. It is most often provided in the home, nursing home, hospice center or hospital, but it has also been given in homeless shelters, cars or in the street for patients who are homeless. Some patients will go back
and forth between hospice locations, such as between home and the hospital, if needed.

**What services does hospice provide?**
Hospice offers many services to patients and their loved ones. Basic services are nurse and doctor care, medicine management, and emotional and spiritual support. Hospice also provides medications, medical equipment and supplies. Hospices provide volunteer and grief support services. Hospice is designed to give the best total care at the end of life. When you talk with your local hospice, ask how they can help. Describe the patient’s medical history, health, and where care will take place.

**Who is on the hospice team?**
A hospice team has several health care providers. They are experts in managing pain and symptoms. Once you are in hospice, keep a list of the names of everyone on your team. Include their contact information and what type of care they provide. Here are some of the team members you would likely see:

- A hospice doctor oversees medical care. Hospice doctors have special training and skills to manage pain and symptoms. The hospice team also works with other doctors you see.
- A registered nurse is the caregiver the patient and family see most. The doctor and nurse work together to give care. The nurse also informs loved ones about the patient’s health and how to give care.
- A social worker who is an expert in end-of-life matters provides emotional support. The social worker can refer you to local resources and help with end-of-life planning.
- A nurse assistant helps with the patient’s personal care needs. These include bathing, feeding, changing sheets and moving the patient.
- Hospice volunteers may be able to provide routine but helpful services. These include cleaning, fixing meals, running errands, sitting with the patient, listening, and other activities. Be clear when you tell the hospice what volunteers can and cannot do for you and the patient.
- A chaplain can give spiritual support to patients and loved ones. Spiritual issues often come up as a person nears the end of life. Hospice chaplains are trained to help people work through these issues. If a patient already has spiritual assistance, the

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**Advanced care planning**
You have the right to make choices about your medical care. You have this right even if you cannot communicate due to serious illness or injury. An advance directive is a written document that gives specific instructions about your health care. Two concepts you should know about are health care surrogates and living will documents.

**What is a health care surrogate?**
A surrogate is an adult who you appoint to make medical decisions for you in case you cannot make those decisions yourself. This person should know your wishes, values and religious beliefs. You should have complete trust and confidence in this person to speak for you about health care choices. A surrogate can resign by giving written notice. You can choose almost anyone to be your surrogate. You cannot appoint someone who works for the health care facility where you are a patient or resident, unless that person is related to you or is in the same religious order.

**What is a living will?**
A living will is a written document that states your wishes for you in case you are ever in a coma or otherwise unable to speak for yourself. It tells your health care providers and loved ones what kinds of treatments you want and do not want. It is called a living will because it goes into effect while you are alive.
hospice chaplain is still available to provide additional support, if the family wishes.

- Pharmacists, respiratory therapists, psychologists, and physical therapists may help with hospice care. The registered nurse will manage these services.

What should I ask before I pick a hospice?

There may be more than one hospice service in your area. Be sure to ask these questions so you can make the best choice.

- Is it certified by Medicare and licensed by the state? Is it accredited by The Joint Commission or other accrediting bodies?
- Is the hospice for-profit, non-profit, or religious-based? These may have personal importance to you.
- Ask about the kinds of spiritual and grief support, pharmacy support, physical therapy, or any other service you may need.
- What kind of training do hospice team members have? How many are hospice certified? Will those who work with the patient be hospice certified?
- Do they evaluate family satisfaction with services? If so, ask to see the results.
- Does the hospice own an in-patient care unit? Does it partner with hospitals or skilled nursing facilities when special care is needed?
- How involved are volunteers? What tasks can volunteers help with?

What can you expect from the hospice team?

- The hospice doctor is a member of the team and reviews and approves the plan of care. But the patient will not interact as much with this doctor.
- A registered nurse is in charge of the patient’s care. The nurse works with the patient and family to decide the goals of care. The nurse manages the hospice team and informs loved ones about the patient’s care. The nurse also coaches family caregivers to give them confidence that they can do their part in their loved one’s care. The nurse visits as often as needed to make sure the goals of care are met.
- Social workers, chaplains, nurse assistants, and volunteers all support the patient and family as needed. This is based on how much help the patient and family caregivers want.
- You may contact a hospice nurse at any time to respond to patient and family needs. These may include managing pain and symptoms or helping with patient care.
- Your hospice team will try to prevent any unneeded medical tests or procedures and trips to the emergency department or hospital.
- Family can use bereavement services for 13 months after death.
Important conversations to have about hospice

Is hospice an option for the patient?
Making choices at the end of life can be hard. This causes many patients to enroll in hospice too late to get all the benefits. There are many reasons for delay. Patients may not want to accept their terminal diagnosis. They may not want to burden their loved ones with giving care. Their loved ones may not be willing to accept that the patient is facing the end of life and that care will focus on comfort over a cure. When you decide about hospice care, be sure to start these conversations with your loved ones and the hospice team.

Are the patient and family ready to accept hospice?
To accept hospice, some people must first accept that the end of life is near. They also need to know that hospice does not take the place of family caregivers. Hospice care offers added support and expertise. In addition, hospice care can last six months or longer. The family should decide how much caregiver support they can give. Some families are not able to care for patients at home. There may be a conflict when a family member wants help from hospice but the patient does not. Also, the family may not be sure what hospice could add to the patient’s current care. Conversations with your hospice can help you make these hard decisions.

Are the patient’s doctors ready to approve a referral to hospice?
There are many reasons why hospice referral may be delayed. It may be hard to estimate how much time the patient has left. The doctor may not want to discuss hospice with the patient or family. The doctor may not know all the services hospice provides. Ask the doctor about the positives and negatives of treatments that would help the patient live longer. Find out if these treatments are likely to extend life. If you think hospice may be an option, start a conversation with your doctor.
Patients or their loved ones can start the referral process if the doctor cannot. Work with your nurses or social worker already involved in the patient’s care or call your local hospice for help. Describe the patient’s situation, medical history and health. The hospice can then start the discussion with the doctor. Patients who start the process early tend to be more satisfied with hospice.

How will you and your family deal with health problems that affect the patient’s quality of life?
Should pneumonia or a broken bone be treated? Treatment may be good if it will improve the patient’s quality of life. At other times it is OK to not treat when it is part of the dying process. Loved ones often feel guilt when they do not aggressively treat every health problem. Talk to your hospice team early about this subject.

Care for the caregivers
Family caregivers provide most of the care for hospice patients. These caregivers may have to handle the patient’s household, finances, and physical and emotional care. These challenges may cause caregivers more stress, health problems, and lower quality of life. Many caregivers find respite care very helpful. Respite care is care provided by others that takes some of the burden off the primary caregiver. Ask your hospice what types of respite services are available. Volunteers may provide these services:

About UK HealthCare hospice programs

The adult hospice program at UK Albert B. Chandler Hospital began in 2010; the Kentucky Children’s Hospital Hospice program began in January 2012.

These programs are for short-term acute medical needs that can’t be treated in the home or a nursing home.

Visit ukhealthcare.uky.edu or call 800-333-8874 for more information about UK HealthCare’s hospice programs.
• Watching and spending time with the patient, even overnight.
• Taking the patient to outings or doctor visits.
• House cleaning or delivering meals.

How do we pay for hospice?
If a patient is eligible, Medicare, private health insurance and Medicaid (in 43 states) cover hospice care. Hospice is covered by Medicare for patients with a life expectancy of six months or less. Medicare covers most services related to the illness. It includes doctor and nursing services, medical supplies, counseling, home care and social workers. Patients may be charged co-pays for medicines and medical equipment. Private insurance and veterans' benefits may cover hospice care in some cases. In addition, some hospice programs offer health care services on a sliding fee scale for patients with low income. Medicaid in Kentucky covers hospice care, and all 120 Kentucky counties are served by hospice.

About Hospice of the Bluegrass
Hospice of the Bluegrass is a private, non-profit hospice that offers care in 32 counties in central, southeastern and northern Kentucky. Hospice of the Bluegrass is:
• A member of the National Hospice and Palliative Care Organization.
• Certified by Medicare and Medicaid.
• Licensed by the State of Kentucky.
• Accredited by The Joint Commission.

Hospice of the Bluegrass has a large library of books on dying, hospice care and related topics. It is open to the public 8:30 a.m. to 5 p.m. Monday through Friday.

Call 800-876-6005 or visit www.hospicebg.org for more information about Hospice of the Bluegrass.

UK HealthCare and Hospice of the Bluegrass are partners. They work together to provide inpatient and outpatient services for adults and children.
Tips from family members who have experienced hospice

Advocate for the patient

1. The patient and family are in charge. Be sure to speak up and assert yourself if you need more information about treatment or treatment changes. Be involved in discussing care goals and the care plan. Always tell your nurse if you do not feel right about the care.

2. Hospice experts are available by phone 24/7. If your loved one has pain or trouble breathing, call anytime day or night.

3. Ask to be briefed about the hospice team meeting. It is usually held every two weeks. Find out if you can take part in the hospice team meetings.

4. If you believe a curing treatment could help the patient, the family or patient has the right to revoke hospice at any time. The patient can have the treatment then return to hospice if it is still necessary.

Become informed

5. Talk to others who have used hospice to learn from their experience. Your hospice can help you contact someone.

6. Most hospices have a handbook for the family. Ask for it if you do not get one.

7. Take advantage of volunteer services. Ask them to come over early and often. This helps the patient and caregivers get to know them. They can often read, play music or talk with the patient. They can give you a break from care.

Take advantage of hospice center counseling and advice

8. Hospice can help with documents like advance directives and living wills. These will help family and loved ones know the patient’s wishes.

9. Nursing homes and assisted living facilities may have different rules and policies for hospice. If you need to move the patient to a nursing home, ask your hospice social worker for advice and support. Visit often to make sure the patient’s wishes are being met. Set up meetings between you, the hospice team and the nursing home staff. This will make sure you are all on the same page.

10. When members of the family disagree about care, ask your hospice team for help. And you can call the hospice hotline for assistance in mediating discussions.

11. When caring for a patient, you may need a break. Ask your hospice team for help. Asking for help is not a sign of weakness.

12. Hospice is not involved in the organ donation process. If the patient wants to donate their organs the hospice team will connect them to the appropriate agency.

13. Hospice continues after the death through bereavement (grief) support. Take advantage of the counseling services for 12 months after the patient dies. Bereavement support can also help children. The needs of children can be overlooked as they may not talk about them.