

WHAT IS HOSPICE CARE, ANYWAY?

By Rev. Maria Hoaglund

If you send forth love to others, you will receive in return the reflection of that love; and you will shine a light that will brighten the darkness of the time we live in—whether it is in the sickroom of a dying patient, on the corner of a ghetto in Harlem, or in your own home.

— Elisabeth Kübler-Ross, M.D.

Hospice has its roots in the concept of hospitality. In the beginning Middle Ages, hospices were European monastic communities where weary pilgrims were given respite. In more extreme cases, the pilgrims were offered comfort and care for serious illnesses and even given assistance in dying.

Today, the term hospice has taken on a more specific meaning. A modern hospice is a place where people can receive assistance in the process of letting go of earthly life. It may be an actual place, like a unit in a hospital, or more often, it is a team of trained professionals who support the dying person through their last stages of life. The team members usually come to visit the homes of individuals on hospice.

The key requirement in hospice is that an individual must be considered by a physician to have less than six months to live. Once on hospice, that person usually will no longer be receiving aggressive curative treatment or diagnostic studies.

One of the main goals of hospice care is to teach and work with the family or network of friends and caregivers so that they can take care of their loved one at home, or wherever the loved one lives. It is a co-creative process. Families are able to do so much with a little bit of information and hands-on demonstration. Usually, a registered nurse acts as the case manager,

managing the medications and serving as the liaison between the individual on hospice and the doctors. But an entire hospice team can get involved in the process, to assist in various aspects of the care-giving needs. Besides the nurses, this team typically involves: a home health aide, a social worker, a spiritual counselor (chaplain), a volunteer, and sometimes a physical or occupational therapist. There is also a hospice consulting physician on board the team, as well as a pharmacist and sometimes a dietitian.

The following are some frequently asked questions and answers about hospice that I found in a brochure entitled, "You matter to the last moment of your life," published by The National Hospice and Palliative Care Organization. (I have edited and used only a portion of the questions.)

1. When does a decision need to be made about when to go onto a hospice program?

At any time during a life-limiting illness, it's appropriate to discuss all of a person's care options, including hospice. By law, the decision belongs to the person him/herself.

The person dealing with the illness and their family can bring up and discuss hospice care at any time with any of their doctors, other healthcare professionals, members of the clergy, or friends. For further education and information about hospice, contact a local hospice program, the American Academy of Hospice and Palliative Medicine (www.aahpm.org), the National Hospice Helpline (800-658-8898), or The Hospice Education Institute (www.hospiceworld.org) (207-255-8800 or 800-331-1620).

2. Once a person is on hospice, if they show signs of recovery or improvement, or if they decide to pursue further treatment, can they return to receiving regular medical treatment?

Certainly. If improvement in the condition occurs or the disease seems to be in remission, the person can be discharged from hospice and return to more aggressive therapy or go on about his or her daily life.

If a discharged person later needs to return to hospice care, Medicare and most private insurances will allow additional coverage for this purpose.

3. What does the hospice admission process involve?

A hospice staff nurse will contact you and interview you over the phone to get an initial assessment. Then, if it looks as though you are eligible, a hospice RN will likely come to where you or your loved one reside to sign you up for hospice care. Your doctor will be contacted to make sure that he or she agrees that hospice care is appropriate for you at this time. You will be asked to sign consent and insurance forms that are similar to the forms you sign when you enter a hospital. The emphasis will be on palliative care, aiming for pain relief and symptom control, keeping the person comfortable through their end of life.

4. Is there any special equipment or changes I have to make in my home before hospice care begins?

Your hospice provider will assess your needs, recommend any necessary equipment, and help make arrangements to obtain it. Often the need for equipment is minimal at first, and increases as the disease progresses. Hospice will assist in any way it can to make home care as convenient, clean, and safe as possible.

5. How many family members or friends will it take to care for a person at home? Does someone need to be with the person at all times?

There's no set number. One of the first things a hospice team will do is prepare an individualized care plan that will address the amount of care-giving a person will need. Hospice staff will visit regularly and are always accessible to answer questions and provide support.

In the early weeks of care, it is usually not necessary for someone to be with the person all the time. Later, however, since one of the common fears of people is the fear of dying alone, hospice generally recommends that

someone be with the person continuously. Family and friends need to be relied on to give much of the care; there are also agencies that can provide caregiving support at these times – anywhere from a few hours a day to 24-hour a day care. Hospice does provide volunteers, when they are available, to help with errands and to provide a half-day break and “time away” for the major caregiver involved.

It's rarely easy to care for someone who is dying – sometimes it can be quite challenging, especially physically and emotionally. At the end of a long, progressive illness, nights especially can be long and lonely. This is why hospice programs have staff available around the clock to consult with the family and to make night visits as appropriate.

6. How does hospice help to deal with the pain? And how successful are they in helping to keep the pain to a minimum?

Hospice nurses and doctors are up-to-date on the latest medications and devices for pain and symptom relief. In addition, physical and occupational therapists assist patients to be as mobile and self-sufficient as possible. Sometimes specialists are available who are trained in music therapy, art therapy, massage therapy, diet counseling, and other integrative therapies.

Hospice believes that emotional and spiritual pain are just as real as, and sometimes even tied in with, physical pain, so hospice addresses these, too. Bereavement Grief counselors including social workers and spiritual counselors are available to assist family members as well as patients. Guided imagery and meditation, essential oils, herbal and homeopathic remedies, acupressure, healing touch, and other kinds of healing modalities can be useful to promote relaxation and the reduction of pain. The counselors and therapists may suggest these modalities to you, but if not, you are encouraged to look into them yourself. (See Chapter Eleven 11 of my book, ***THE LAST ADVENTURE OF LIFE***, or my website links for more ideas in this area.) Almost always hospice can help greatly with reducing and even

eliminating pain. Using a combination of medicine, counseling, and other modalities of healing, most people are able to attain a level of comfort that is acceptable to them.

7. Will medications prevent the patient from being able to talk or be aware of what's happening?

Usually not. It is the goal of hospice to help people be as comfortable and alert as they would like. By consistently consulting with the patient, hospices have been highly successful in reaching this goal.

8. Is hospice affiliated with any religious organizations?

Hospice care is not an offshoot of any religion, though its roots are connected to a ritual of hospitality that was offered to pilgrims and sojourners in churches religious communities in the Middle Ages. While some religious organizations have started hospices, sometimes in connection with their hospitals, these hospices usually serve a broad community and do not require people to adhere to any particular set of beliefs. In fact, it is the goal of the hospice's spiritual counselors and chaplains to encourage and develop the spiritual life of the people we meet. We encourage people right where they are on their spiritual journeys and in a way that is the most comfortable and appropriate for them.

9. Is hospice care covered by insurance? If not, will hospice still provide care?

Hospice coverage is widely available. Coverage is available through Medicare nationally, through Medicaid in some forty-two states, and through most private health insurance policies. To be sure of coverage, families need to check with their employers or health insurance providers.

Hospice will help assist families in finding out whether or not their loved one is eligible for any coverage they may not be aware of. Barring this, many hospices will provide care for those who cannot pay, using money raised from the community, or from memorial or foundation gifts.

10. Does hospice provide any help to for the family after the loved one dies?

Hospice provides continuing contact and support for family and friends for at least a year following the death of a loved one. Most hospices also sponsor bereavement and support groups for anyone in the community who has experienced the death of a family member, a friend, or a loved one. There are also bereavement coordinators associated with most hospices who can point you to other resources that you might be able to utilize use at this highly emotionally sensitive and exhausting time. There is tremendous opportunity for growth and healing at a time when one is grieving; it is to your advantage to make the most of all the resources available to you. (See Chapter Ten 10 of my book for more information related to grief and loss.)

I want to close by sharing a poem written by a hospice nurse to a dying patient for whom she was caring. Notice the tremendous love and sense of commitment that is shared in this "pledge."

My Pledge

You are dying.
I know it, and I won't deny it.
I won't give you false assurances or false hope.
But I'll give you the comfort you seek.

I'll hold your hand.
I'll listen without judgment when you cry
"Why me?"
I'll support you when you cry,
And dry away your tears.

I will be near.
When you want to be left alone, I'll leave.
But when you need me,
I'll be there.

When you are gone
I'll stay by your family.
I'll let them know you died in peace.
And that when they were there you knew it.
And how much you loved them all.

When you are gone, I'll remember
How you helped me.
You taught me so much about life.

When you are gone, I'll remember
How much I loved you.

Rev. Maria "Dancing Heart" Hoaglund is United Church of Christ minister and hospice spiritual & bereavement counselor who self-published a unique, inspirational book for healing and prayer in 2005. The second edition, ***The Last Adventure of Life: Sacred Resources for Living and Dying from a Hospice Counselor***, is now available through your local bookstore. See her website: www.thelastadventureoflife.com for "**GRIEF POINTERS: Ten Ways to Honor Your Grief**" and other resources related to hospice care and the integrative therapies, tools for relaxation and healing. Or call: **(888) 409-1678** to order Maria's book or one of her unique Soul Baskets (www.soulbaskets.com).