About Hospice Care

People may decide to enroll in hospice care when they are at a turning point in their illness. The focus of hospice care is on comfort care and symptom management – not on a cure. Hospice services are available to people of any age, religion, race or illness. These services are provided by many community agencies.

Hospice care is usually given at a person’s home, but the hospice team can also provide care to people in special facilities, hospitals or nursing homes. The hospice staff makes visits to guide the care of the patient. The hospice staff cares for both the ill person and those who provide support and care to the ill person.

Reasons Why People Choose Hospice Care

- The doctor has told them that the benefits of more treatment are small and that a cure is not expected.
- The ill person may be tired of having treatments or being in the hospital and decide they do not want any more treatments that are aggressive or prolong life.
- The person may not want further tests, x-rays, scans or other procedures.
- The person may only want palliative care. This type of care provides comfort, emotional support and symptom management to help the patient live each day to the fullest by making them comfortable.
- The person may realize that they are nearing the end of life and they do not want aggressive treatments including cardiopulmonary resuscitation (CPR).
• Many people complete advance directives to make their wishes known about their health care choices. Advance directives tell your doctors and other health care workers what types of care you would like to have, and the person you would like to speak on your behalf, if you are not able to make medical decisions.

The Hospice Care Team

The hospice care team includes:

• Your **doctor** or a hospice doctor to direct the care you receive from hospice. If your doctor is unable to continue to direct your care when you enroll in hospice care, the hospice doctor will provide this service.

• A **nurse** makes visits based on the needs of the patient and caregivers. The nurse makes sure the patient is comfortable and that the caregivers know how to provide care.

• A **hospice aide** makes visits to provide personal care and supports the caregivers in the care they give to the patient.

• A **social worker** visits as needed to help the patient and caregivers with emotional and practical concerns.

• **Spiritual care** is also available to help the patient and caregivers in spiritual or religious matters.

• **Speech, occupational or physical therapists, counselors or homemakers** may also work with people in hospice care when needed.

• Trained **volunteers** help patients and caregivers in many practical ways. They may help with errands, stay with the ill person while others shop, or may even help with walking a dog.

• The **hospice care team** provides guidance and support, but they do not replace the role of the caregivers.

• Follow-up **bereavement care** is offered to caregivers by members of the hospice care team for one year after a person’s death.
The Important Role of Caregivers

A person who chooses to use hospice care at home usually has one or more caregivers. Caregivers are family members or friends who are willing to provide care when the person is no longer able. Most caregivers say that giving home care is satisfying and rewarding, but also very difficult. Caregivers need to take steps to stay well and healthy themselves. The hospice staff can provide them with help and support.

Caregivers need to be willing to learn how to provide care. They may need to:

- Give medicines.
- Do treatments if needed, like caring for a wound.
- Help the person with their personal care, such as bathing or cleaning up after an accident in the bed.
- Make sure the ill person is kept safe from harm. For example, not allowing smoking in the room if the ill person is on oxygen.

When needed, caregivers may have to make arrangements for extra help so the ill person has someone with them at all times. Some may hire a nurse to help with the care of the ill person. Others may need to have the patient go into a nursing home where the hospice team will continue to direct their care.

It is important that all caregivers honor their loved one’s decision to have hospice care and to stop further treatment. Caregivers will be asked to call hospice if a problem develops. They will be asked not to call the emergency squad or “911”. This helps prevent the ill person from having to go through emergency medical care procedures.

Other Benefits of Hospice Care

- **Symptom Control**

  A person might be admitted to an inpatient hospice unit to help control a problem or symptom. This would be done to help find the best way to manage a difficult symptom. An inpatient hospice unit may be a special unit within a hospital, another medical facility or in its own building.

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• **Respite Care**

Sometimes a person may be admitted to an inpatient hospice unit to give regular caregivers some time off or time away. This is called respite care. Sometimes caregivers need a break, or they may be ill. A stay in an inpatient hospice unit lasts a week or less. Respite care may be done every few months.

• **Other Services**

Hospice care includes many other services and benefits. It can help provide some medicines, home medical equipment, supplies and hospital services. Sometimes hospice can help provide or arrange for extra help in the home.

**Medicare and most insurance plans cover the costs for hospice care.**

Many resources are available to help pay for hospice care, even if you are unable to pay or do not have insurance coverage.

**How to Arrange Hospice Care**

• If you think you might want hospice care, talk to your doctor or nurse and ask to see a social worker. The social worker can give you information about the agencies that provide hospice services and get the referral needed from your doctor to make the arrangements.

• If you live in another area, the social worker can make the referral to a hospice in your area. You may also contact the National Hospice and Palliative Care Organization at [www.nhpc.org](http://www.nhpc.org) or their helpline at 1-800-658-8898 for information or to find a local hospice.