

Starting Hospice



If you're thinking about hospice, you know that the decision can be a difficult one. It means that you or your loved one is nearing the end of life. It is normal to feel very emotional when hospice is discussed. Some people and their families may feel choosing hospice means they are giving up. But in many ways deciding on hospice care is choosing to have control and an active role in the last stages of one's life.

You or your loved one's healthcare providers can help guide you in making the decision. But keep in mind that the goal of hospice is to provide comfort. This is done for both the person who is ill and their family. Hospice is about providing compassionate care and making sure of the quality of life for the time a person has left. Emotional and practical matters are taken care of while symptoms are controlled.



Beginning the hospice process

A healthcare provider must confirm that you or your loved one qualifies for hospice. A person with advanced cancer, heart failure, severe lung disease, or other illness can go into hospice when a provider believes they have about 6 months or less to live. You can then choose a hospice to make this time as comfortable as possible.

Choosing a hospice

When you are looking at hospices, ask questions. What are their services? Where do they provide care : at home or in a facility? Ask for a copy of the hospice's Patient's Rights and Responsibilities. To learn more about your local hospices, contact:

- Healthcare providers or hospital case managers or home care staff
- Your place of worship
- The local agency on aging
- The Veterans Health Administration office
- State department of health or social services
- The state hospice organization
- [National Hospice and Palliative Care Organization, www.nhpco.org](http://www.nhpco.org)
- [Hospice Foundation of America, www.hospicefoundation.org](http://www.hospicefoundation.org)

The hospice team

Hospice is provided by a team. The team often has a healthcare provider, a nurse case manager, and social worker trained in hospice care. It may also have a home health aide, spiritual counselor, and volunteers. The people receiving treatment are the center of the team. They can voice their wishes and goals. If hospice is done at home, family members give day-to-day care. A hospice aide can make several visits each week to help with bathing and bathroom needs. The number of visits made by the hospice aide is decided by the hospice team and depends on the needs of each client. A nurse, social worker, and other professionals will also visit. A hospice nurse or healthcare provider is on call 24 hours a day to answer questions and handle problems. Ask your healthcare provider if they participate in a hospice program if you wish to stay under their care while enrolled in a hospice program. If they don't participate, your hospice care can be managed by the hospice program's medical director. If you choose, the hospice team can keep your primary healthcare provider informed of your health.

Preparing for care at home

Hospice is often done in the home. Family members are the main caregivers. They get support from the hospice team. The team may help you arrange care. They can provide medical equipment as needed. This may include a hospital bed, commode, oxygen, or other supplies. The hospice team can also help the family get breaks from caregiving. This is called respite care. For a short time, the person receiving hospice care can be put into a facility. This lets caregivers take care of other needs. If hospice is already being done in a facility, all of these things are taken care of on site.

Physical care

Hospice care focuses on the person's quality of life and comfort. Symptoms are actively treated. These include pain, nausea, anxiety, breathing distress, and sleep problems. The hospice program will provide medicines to ease these symptoms. Treatments that are no longer helping may be stopped. The team will discuss what treatment changes may be needed. Caregiver education is provided on giving medicine, managing symptoms, and giving physical care. Questions from caregivers and family members are encouraged.

Emotional care

The hospice team provides compassionate emotional support for both the person and their family. When the family is ready, the hospice nurse can explain the dying process and what changes they may see as their loved one's condition changes. The team will also teach the family how to recognize symptoms and provide comfort measures. A team member is available to call 24/7 when crises or questions arise. No caregiver is left alone trying to figure out what to do. Both the person receiving treatment and family members can get counseling. This is to help with anxiety, grief, family conflict, and spiritual issues. Bereavement support can continue up to 1 year after the person dies.

Practical matters

The hospice team helps the person receiving treatment and family members understand the illness and how it progresses. They can help both the person and family members review choices so decisions can be made. The team can help with finding legal resources and answering insurance questions. And they give information about how to make funeral and memorial arrangements.

Stopping hospice

The person's primary care provider will have contact with the hospice team on a regular basis. If the person's health improves, they may no longer meet the terms for hospice or need hospice care. In this case, the person can end the hospice care. They can start it again later as needed. A person can go back to hospice at any time. They must be recertified by a healthcare provider. Also, a person has the right to leave a hospice at any time for any reason. A person can also change to a different hospice if they're not happy with the care.

The cost of hospice care

Medicare, Medicaid (in some states), and most private health insurance plans cover hospice care. Families may be asked to meet some costs that aren't covered by insurance. Public and community support make it possible for hospices to cover the cost of care. This happens through donations, grants, memorial gifts, and fundraising events. People are generally not turned away for financial reasons.

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