

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities



American Cancer Society Circle Of LifeSM
Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:
Nearing the End Of Life

Revised October 2015

Chapter 4: Hospice Care



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Hospice Care

Group Discussion			
	True	False	Not Sure
1. There is no difference between palliative care and hospice care.			
2. Palliative care begins at diagnosis and continues during cancer treatment and beyond.			
3. Hospice care begins one year prior to the end of life.			

Palliative care is different from hospice care. Both palliative and hospice care share the same principles of comfort and support, but palliative care differs because it begins at diagnosis and continues during cancer treatment and beyond. Palliative care addresses the emotional, physical, practical, and spiritual issues of cancer during treatment and at the end of life when a person may be in hospice.

How is palliative care given at the end of life?

Making the transition from treatment that intends to cure cancer to end-of-life care is a key part of palliative care. Near the end of life, palliative care is often used alone in hospice settings. The hospice team can help patients cope with the different thoughts and emotional issues that arise, such as worries about leaving loved ones behind, reflections about their legacy and relationships, or reaching closure with their life. In addition, palliative care can support family members and loved ones emotionally and with issues such as when to stop trying to treat the cancer, grief counseling, and transition to hospice.

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Hospice is a program designed to give supportive care near the end of life. The right time for hospice care is when treatment aimed at a cure is no longer helping someone.

Hospice sees death as the natural, final stage of life. It seeks to manage a person's physical and emotional symptoms. Its focus is on quality of life, rather than its length.

Hospice programs offer family-centered care. They involve the person with cancer and family in making decisions. Hospice care is usually given in the home. But there are a few hospitals that offer hospice care and some private hospice centers. Hospice care is also offered in some nursing homes.

In a hospice program, a team will usually care for the person with cancer. The team will have a medical director who is a health care provider, a nurse, a nurse's aide, a social worker, and a chaplain. In most cases, the person's own health care provider will also play a role.

It can be hard to decide to start hospice care. In general, it means someone is ready to stop treatment aimed at curing the cancer. A person can only enter hospice if they are expected to live about six months or less if the illness runs its usual course. But sometimes people in hospice can live longer. Together, the person with cancer, family, and health care provider decide when hospice care should begin. Many professionals in the field notice that many people are referred to hospice within days of death. There is much that a hospice program can do to help a person's quality of life, but it can help more if they have at least a few weeks to work on it.

Most hospice programs do not allow someone to get treatments such as chemotherapy, radiation, transfusions, or IV nutrition. An honest talk with a health care provider can help a person decide if that is the right thing to do. Ask

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whether any treatment the health care provider suggests offers hope for a cure. If a cure is not possible, will the treatment prolong life or relieve symptoms?

A person should think about hospice if their health care provider can't assure them that treatment will meet any of these goals. A hospice program may give the best chance of controlling symptoms and providing quality of life. Most experts in palliative care observe that people enter hospice programs too late to get their full benefit.

Choosing Hospice Care

Hospice care puts a person and their loved ones in the care of experts at the end of life. The goal of hospice care is to help someone live their last days as alert and pain-free as possible. Hospice care aims to manage symptoms so that a person's last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease; it focuses on quality of life. It provides family-centered care, involving the person with cancer and their family in all decisions.

This care is planned to cover 24 hours a day, seven days a week. Most hospice care in the United States is given in the home, with a family member or friend serving as the main caregiver. If a person wants home hospice care, a caregiver must be in the home with them 24 hours a day.

Hospice care is used when a person can no longer be helped by treatment that aims to cure. The person, their family, and their health care provider decide together when hospice services should begin. If a person gets better or the disease goes into remission, they can be discharged from the hospice program and return to active cancer treatment if they wish. Hospice care may be resumed at a later time if needed.

Making the choice to get hospice care should not be viewed as a last resort. The benefits that a person and their family can get from hospice care are very

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valuable. Through hospice care a person will get help to put their affairs in order, say their good-byes, and spiritually prepare for death in a way that promotes dignity and comfort. The family will be fully supported through the dying process and helped through grief and bereavement.

Even though it is common to hear that someone must expect to have six months or less to live, other standards are also used to decide if a person with cancer can enter hospice. In most cases, a person must have widespread, aggressive, or progressive disease. This means worsening symptoms, worsening lab values, and/or signs of metastasis (the spread of cancer cells to distant areas of the body). They must also be unable to work or do certain things. Finally, they must have either refused life-prolonging therapy or have been getting worse in spite of treatment.

Who Gives Hospice Care and What They Do

There are things about hospice care that make it different from other health care. Hospice care is mainly palliative care. Palliative care is treatment to relieve physical and emotional symptoms. It focuses on comfort and increases well-being. Hospice staff members are specially trained to help a person with cancer and their loved ones through this very difficult time. The knowledge and experience they can share can help a person to have the very best quality of life right up until the very end.

Hospice care uses a health care team that often consists of:

- Oncologists (cancer specialists)
- Primary care physicians
- Physicians who specialize in palliative care
- Nurses

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- Social workers
- Pain specialists
- Physical or occupational therapists
- Dietitians
- Pharmacists
- Counselors
- Spiritual or faith-based advisors

Each team member offers support based on their special areas of expertise. Together, they give complete palliative care. Their goal is to improve a person's quality of life by taking care of the following:

Pain and Symptom Control: The goal of pain and symptom control is to help a person to be comfortable while allowing them to stay in control of and enjoy their life. This means that side effects are managed to make sure that they are as free of pain and symptoms as possible, but still alert enough to enjoy the people around them and make important decisions.

Spiritual Care: Hospice care also tends to the spiritual needs of a person and their family may have. Since people differ in their spiritual needs and religious beliefs, spiritual care is set up to meet specific needs. It may include helping them to look at what death means, helping to say good-bye, or helping with a certain religious ceremony or ritual.

Home Care and Inpatient Care: Even when hospice care is based in the home, a person may need to be admitted to a hospital, extended-care facility, or an inpatient hospice facility. Hospice can arrange for inpatient care and will stay involved in with a person's care and with their family. A person can go back to in-home care when they are ready.

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Respite Care: While a person is in hospice, their family and caregivers may need some time away. Hospice care may offer them a break through respite care, which is often given in up to five-day periods. During this time a person will be cared for either in a hospice facility or in beds that are set aside for this in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while their loved one is cared for in an inpatient setting.

Family Conferences: Through regularly scheduled family conferences, often led by the hospice nurse or social worker, family members can stay informed about their loved one's condition and what to expect. Family conferences give everyone a chance to share feelings and talk about what they expect. It can also help the family learn about death and the process of dying. Family members often find great support and stress relief through family conferences. Conferences may also be informal as the nurse or nursing assistant talks with a person and their caregivers during their routine visits.

Bereavement Care: Bereavement is the time of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to loved ones through visits, phone calls, and/or letter contact, as well as through support groups. The hospice team can refer family members and caregiving friends to other professional care if needed. Bereavement services are often provided for about a year after a loved one's death.

Volunteers: Hospice volunteers play an important role in planning and giving hospice care in the United States. Volunteers may be health professionals or lay people who provide services that range from hands-on care to working in the hospice office or fundraising.

Staff Support: Hospice care staff members are kind and caring. They communicate and listen well, and are interested in working with families who are coping with a

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life-threatening illness. They are usually specially trained in the unique issues surrounding death and dying. Yet because the work can be emotionally draining, it is very important that support is available to help the staff with their own grief and stress. Ongoing education about the dying process is an important part of staff support.

Coordination of Care: The hospice team coordinates and supervises all care seven days a week, 24 hours a day, seven days a week. This team is responsible for making sure that all involved services share information. A person with cancer and their caregivers are encouraged to contact their hospice team if there is a problem, anytime, day or night. There is always someone on call to help with whatever may arise. Hospice care assures people that they are not alone and help can be reached at any time.

Where Hospice Care Is Provided

Hospice care can be given in:

- Someone's home
- A hospital
- Nursing home
- Private hospice facility
- Inpatient hospitals
- Outpatient clinics
- Skilled nursing or assisted living facilities

Finding Hospice Care

Finding the hospice program that best meets a person's needs may take some research, but it will be time well spent. It is important that a person and their

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family do this while they have the strength and ability to do so. Quality of care, availability of needed services, the types of services covered, staff training and expertise, and insurance coverage are all things to think about. Most communities have more than one hospice provider. Ask around about others' experiences with hospices. Other resources are listed at the end of this module, but here are some other ways to start the search:

Local Resources: A health care provider or hospital discharge planner can help find hospices in the area. Hospice care providers are often listed in the phone book. A person may be able to contact the local American Cancer Society, an Agency on Aging, a local United Way chapter, the Visiting Nurse Association, or a place of worship for information on hospices nearby.

State Resources: A person can contact their state's hospice organization or its department of health or social services to get a list of licensed agencies. The state health department oversees certification of hospice services. Certification qualifies them to be paid by Medicare and, in some states, also from Medicaid. Check the blue pages of the phone book for other state resources in the area.

National Resources: National organizations that address hospice accreditation, treatment, and patient advocacy are listed in Appendix D.

Paying for Hospice Care

Home hospice care usually costs less than care in hospitals, nursing homes, or other institutions. This is because less high-cost technology is used and family and friends provide most of the care at home.

Medicare, Medicaid, the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care plans may pay for hospice care. Along with this, community and memorial donations and foundation gifts allow many hospices to give free services to people who can't afford to pay. Some programs

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charge people based on their ability to pay. To get payment from Medicare, the agency must be approved by Medicare to provide hospice services.

To qualify for the Medicare hospice benefit, a health care provider and the hospice medical director must certify that a person has less than six months to live if the disease runs its normal course. The health care provider must re-certify someone at the beginning of each benefit period (two periods of 90 days each, then an unlimited number of 60-day periods). The person signs a statement that says they understand the nature of the illness and of hospice care, and that they want to be admitted to hospice. By signing the statement, the person declines Medicare Part A and chooses the Medicare hospice benefit for all care related to their cancer. The person can still receive Medicare benefits for other health problems. A family member may sign the statement if their loved one is unable to do so.

Medicaid Coverage: In 1986, laws were passed to allow states to develop coverage for hospice programs. Most states have a Medicaid hospice benefit, which is patterned after the Medicare hospice benefit.

Private Insurance: Most private insurance companies include hospice care as a benefit. Be sure to ask about insurance coverage, not only for hospice, but also for home care.

Private Pay: If insurance coverage is not available or does not cover all costs, a family can hire hospice providers and pay for services out of pocket. Some hospices are able to provide services without charge if a person has limited or no financial resources.