



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

Wellness along the Cancer Journey:
Palliative Care
Revised October 2015
Chapter 4: Home Care



Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Home Care

Group Discussion			
	True	False	Not Sure
1. Hospice care is the same as home care.			
2. Home care is care given outside of the hospitals and medical visits.			

Choosing Home Care

Caring for the sick at home is the oldest form of health care. Whether a person is being treated for cancer, is recovering from it, or has advanced disease, home care might be an option. A wide range of health and social services can be given at home to people with cancer.

Many home health care agencies offer care and support for people who choose to stay at home. Home care usually includes regular visits by health care professionals. But the family is still responsible for most of the day-to-day care. It is important to talk with the cancer care team so that everyone understands what types of care will be needed and how this will affect the family. The family needs to know what is expected of them and work out how they can do it. It is also important to find out whether a health insurance company will pay for home care.

Family and friends are called informal home caregivers. But formal home care is a business that provides care to all types of people with a wide variety of needs. Home care can offer anything from skilled nursing care to homemaking services. Skilled home care services from a certified agency can offer health care and help manage symptoms. They can also teach the patient and family about medicines, central lines, and wound care, to name just a few services.

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A health care provider's prescription is needed for all home care services. In most states a person must meet strict criteria (requirements) to get home care. This can include things like

- A health care provider must decide that the person needs medical care at home and make a plan for that care at home.
- The person must need at least one of the following either part time or on and off: skilled nursing care, physical therapy, speech-language therapy, or occupational therapy.
- The person must be homebound and unable to leave the house without help. To be homebound means that leaving home takes a good deal of effort. But leaving home for medical treatment or short non-medical trips (such as for haircuts or religious services) do not usually disqualify a person.

These are Medicare's guidelines, but they can sometimes make it hard for end-of-life care to be managed through a home care agency.

Many providers offer home care services, including:

- Home health agencies
- Hospices
- Homemaker and home care aide agencies
- Staffing or private-duty agencies
- Medical equipment and supply companies
- Home infusion or pharmaceutical (medicine) companies

Sometimes, several types of home care providers may work together so they can offer a wide range of services.

The choice of a home care agency is an important one for the person with cancer, their family, and their health care provider. To help a person make the best choice, here are the main types of home care agencies and questions to ask them. Different types of agencies may be better depending on the person's health care needs.

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Sometimes, the family can't care for their loved one at home. Sometimes they may start home care but then can't keep doing it. There may not be enough family members to provide all the care needed or the care may be too complex to be given at home. If this happens, family members may feel guilty, especially if they had promised to provide care at home. Recognizing the efforts of family members can help them cope with these feelings.

Types of Home Care Services

If a person needs skilled home care services, they will usually be given by a home health agency. The same agency may offer different kinds of home care services through nurses, therapists, social workers, homemakers and home care aides, medical equipment and supply dealers, and volunteers. Some agencies limit their services to nursing and one or two other specialties. If care is needed from more than one specialist, the home health agency will set up a team to provide care that covers the person's needs. Home care services are usually available 24 hours a day, seven days a week, though most home services are done during the day when possible.

Through a home care agency, a person can get much of the same care and many of the same services as in a hospital. If their needs are simple, they may get one type of care. If not, they may need a combination of services. A health care provider will work with the home health care team to set up a plan of care. This plan includes the services needed, the type of staff best suited to provide those services, and how often the services are needed.

Nursing Care: A highly skilled registered nurse (RN) can be very helpful to care for someone at home and can help relieve the burden on family members. With home care, a nurse comes into the home, looks at the care needs, and sets up a plan of care along with the health care provider. Services may include the care of wounds; ostomy care; giving intravenous (IV) treatments; giving and supervising medicines; and watching for side effects. A person's care plan may also include giving supportive care, like pain control, as well as health teaching and emotional support. The needs of both the person with cancer and the family are covered.

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Physical Therapy: Physical therapists can help a person regain the use of impaired or weakened muscles. They also work with to improve the range of motion in joints and learn to use any special equipment needed for daily activities.

Occupational Therapy: An occupational therapist can help with problems that keep a person from day-to-day activities. They will look at what a person can do, and then teach them new ways to do tasks like eating, bathing, dressing, and household routines. If special equipment is needed, they will be taught to use it. With the therapist's help, a person can learn to do more things on their own.

Speech Therapy: If a person cannot talk the way they used to, a speech therapist can help them communicate again. They can also help a person who is having trouble swallowing. The speech therapist teaches special techniques and helps a person practice.

Social Workers: Social workers look at social and emotional factors that affect people with cancer. They serve as case managers for someone with complex needs and help find sources of help in the community. This can include helping the family look for financial assistance when needed. They can also counsel family on coping with the demands of illness, family conflicts, and grief.

Home Health Aides/Home Care Aides: With the help of an aide, a person can better handle personal care, such as getting in and out of bed, walking, bathing, and dressing. Some aides have had special training and are qualified to give more complex services if supervised by a registered nurse.

Homemaker/Attendant Care: A homemaker can perform light household tasks like laundry, meals, housekeeping, and shopping. These services are done to help maintain a house rather than give health care. Some agencies assign a home health aide these tasks along with the health services.

Volunteers: A volunteer from a community organization, a home care agency, or hospice can give emotional support. They may also help with personal care, paperwork, and getting to and from health care provider visits.

Others: Home care services may also include some of these:

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- Nutrition support and help with diet
- Medical equipment and supplies
- Lab and x-ray studies
- Pharmacy services
- Respiratory therapy
- Transportation
- Home-delivered meals
- Problem-solving or other help by phone
- Dentists, clergy, specialist health care providers, and other health professionals
- Emergency alert or safety monitoring systems

Hospice care is given when the end of the physical life is near:

Hospice care is usually given at home, but it is a special kind of home care. Some cancer centers actually have special palliative care teams that are experts in the challenge of controlling symptoms near the end of a person's physical life. The team usually has professionals with extra training in cancer and hospice care. Hospice team members may include a medical provider, chaplain, social worker, nurses, home health aides, physical therapists, a dietitian, pharmacist, and breathing (respiratory) therapist. The hospice care team works together to:

- Develop treatment plans.
- Manage pain and other symptoms.
- Give emotional support.
- Help deal with issues that are common near the end of physical life.

Hospice care is often begun when the cancer has reached an advanced stage, and the cancer treatment is no longer working. Treatment that is intended to cure the cancer stops, while palliative and comfort care become more important. Hospice must be accepted by the person with cancer and their family before it can begin.

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And, hospice must be prescribed by the health care provider. Hospice care is an important way to keep a good quality of life when a person is no longer being helped by regular cancer treatment.

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Activity

Use the table below as a guide to list palliative care resources in your community. Ask people in your community about additional resources.

Program Name & Location	Program Focus (e.g., treatment, fatigue, pain, transportation, financial assistance, etc.)	Program Type (e.g., group session, one-on-one, service, durable medical equipment, home care, etc.)	Eligibility Criteria (e.g., income limitations, lack of insurance coverage, cancer type or stage, treatment type, etc.)	Limits of Service (e.g., # of sessions, # of rides, # of days, etc.)
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				

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Story of Hope



"So we were able to send her bundle with her on that three-day road. We believe that the spirit takes four days to reach that, that realm of sacredness, that realm where the Creator dwells. And we don't believe in death being final, we just believe it's another step, where we leave this physical earth, to go on to the next and that our relatives that are waiting there and our Creator (Native language) who sits in that sacred realm. We are just being called to another part of home."
Lorraine "Punkin" Shanaaquet, Potawatamie and Ojibwa advocate

(Clark, R., (Producer) & Shanaaquet, P. (Artist). (2007). *Survivor Video Vignettes: Death Beliefs*. [Web]. Retrieved from <http://www.natamcancer.org/vignettes/punkin-palliative.html>)

Key Messages

- Learn about state or health coverage plan guidelines for receiving home health care before they are needed.
- Sometimes it is not possible for friends and family to provide ongoing home care for a person with cancer. They may need to be admitted to a facility for professional care around the clock.
- Medicare, Medicaid, private insurance, or other managed care plans may pay for some types of home care, including hospice care.
- Hospice care is a valuable resource to help people with cancer and their families to put their affairs in order, say their good-byes, and spiritually prepare for death in a way that promotes dignity and comfort.

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