

*Circle Of Life: Cancer Education and Wellness*  
*for American Indian and Alaska Native Communities*



American Cancer Society Circle Of Life<sup>SM</sup>  
*Cancer Education and Wellness for American Indian and Alaska Native Communities*

Wellness along the Cancer Journey:  
**Palliative Care**  
Revised October 2015



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## **WELLNESS ALONG THE CANCER JOURNEY: PALLIATIVE CARE**

**Goals:** Community health workers and care providers will be able to define and discuss palliative care and related issues. They will also understand some common emotional and physical issues addressed by palliative care throughout the cancer journey.

### **Learning Objectives:**

- What is palliative care?
- When is palliative care used?
- How cancer pain can be managed?
- What is the difference between home and hospice care?



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**Wellness along the Cancer Journey: Palliative Care**

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**Chapter 1: Module Overview**



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#### **Module Overview**

This module will look at the type of care given to cancer patients and their families, including pain and other symptoms. Palliative therapy is treatment aimed at relieving symptoms. It is not meant as a cure for the disease (cancer). Most often, palliative care is given along with other treatments that are intended to cure or treat the cancer. Palliative care is also given when a cure is not possible, and even when other treatments have stopped. The main purpose of this type of treatment is to improve the patient's comfort and quality of life at all stages of the cancer journey.

In this module, we will be discussing palliative care as it relates to the cancer journey (diagnosis, treatment, and beyond). Home care will be discussed in this module. Home care for the sick is the oldest form of health care. Today, a wide range of health and social services can be given in the home. Whether a person is being treated for cancer, is recovering from it, or has advanced disease, home care can be an option. Through home care a person can get expert, compassionate health care in the home instead of in a hospital or other facility.

The module on nearing the end of life will discuss hospice, which includes palliative care given near the end of life. This is used when other treatments have stopped working.



# Definitions of Palliative Care

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness -- whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of healthcare providers, nurses, and other specialists who work with a patient's other healthcare providers to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

American Cancer Society, 2011

Palliative care is comfort care given to a patient who has a serious or life-threatening disease, such as cancer, from the time of diagnosis and throughout the course of illness. It is often provided by specialists who work with a team of other health care professionals, such as doctors, nurses, registered dietitians, pharmacists, and social workers.

(The National Cancer Institute. (2010). Palliative Care in Cancer. Accessed April 24, 2015 from <http://www.cancer.gov/cancertopics/factsheet/Support/palliative-care>)

“Palliative Care addresses care needs of people with serious life-limiting illnesses such as cancer. It focuses on bringing comfort and reducing pain to the patient even when cure may not possible.”

-(Alaska Native Tribal Health Consortium. (2009). Cancer Glossary. Retrieved October 8, 2015, from <http://www.anthc.org/chs/crs/cancer/cancerglossary>)

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**Chapter 2: Palliative Care**



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<b>Group Discussion</b>			
	True	False	Not Sure
1. Palliative care is only given at the end of life.			
2. The goal of palliative is to only treat the physical side effects of cancer.			
3. Family members can also be helped by palliative care.			

### **Palliative Care**

The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment. Palliative care also works to prevent and treat any emotional, social, and spiritual problems. The goal of palliative care is not to cure, but to help improve the quality of life. Palliative care is also called *comfort care*, *supportive care*, and *symptom management*.

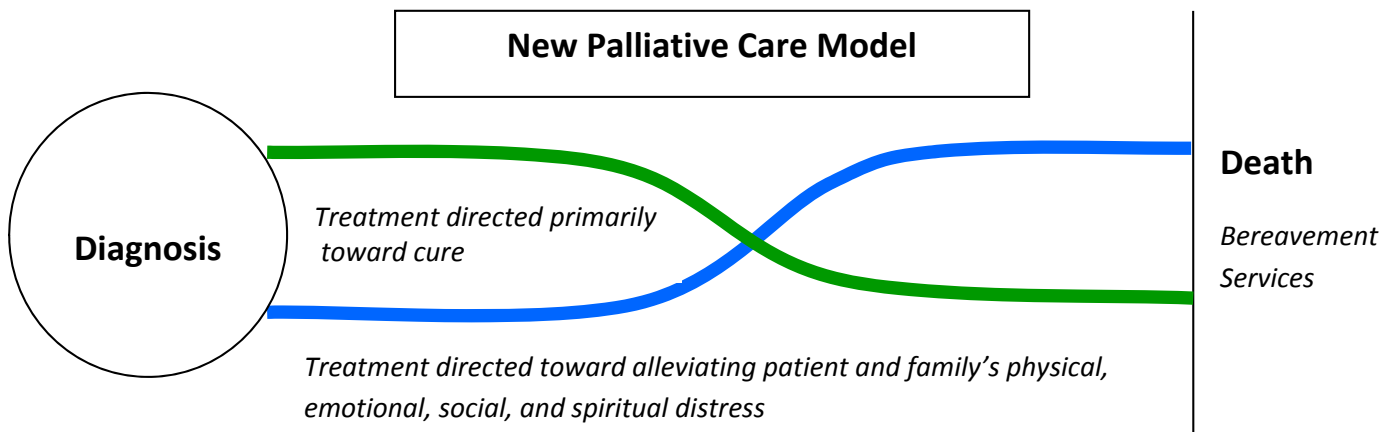
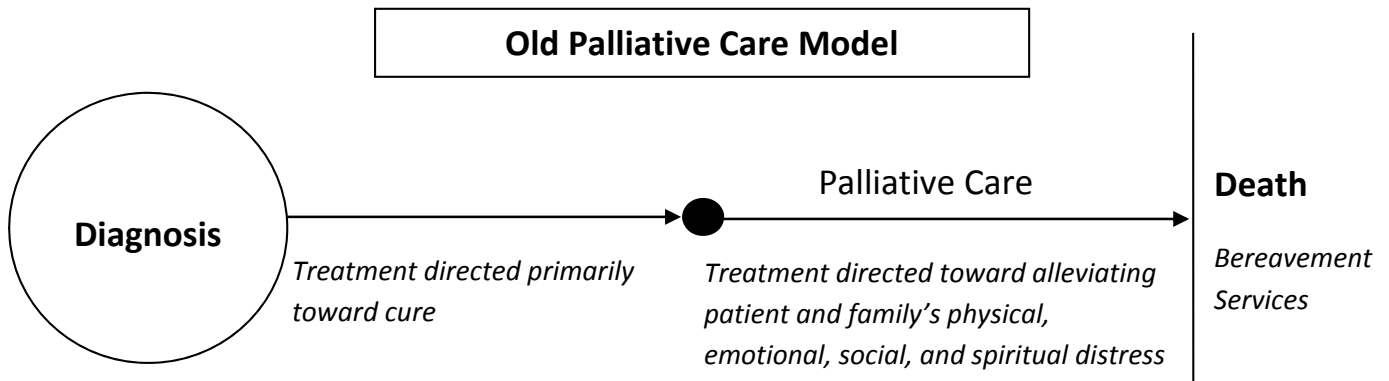
At one time, people thought of palliative care as the kind of care that was offered when nothing else could be done to treat or cure the cancer. But cancer care providers have always worked to relieve symptoms as part of cancer treatment. It's now recognized that palliative care is an important part of cancer care at all stages.

Palliative care should start at diagnosis and be used during treatment and follow-up care, at any time it's needed. If the cancer is not cured, palliative care is also used near the end of life. Family members may also be helped by palliative care.



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(Alaska Native Tribal Health Consortium. (2009). *Models of palliative care*. Retrieved September 15, 2009, from [http://www.palliativeak.org/palliative\\_care](http://www.palliativeak.org/palliative_care))

### What does palliative care do?

The goal of palliative care is to prevent and relieve suffering. It seeks to support the best possible quality of life for people with cancer and their families. This is its goal no matter what the stage of the disease might be.

Palliative care will take all of these factors into account for each patient:

**Physical.** Common physical symptoms such as:

- Pain

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- Breathing problems
- Appetite loss
- Weight loss
- Fatigue (tiredness)
- Depression and anxiety
- Confusion
- Nausea and vomiting
- Constipation
- Trouble sleeping

Many of these symptoms can be relieved with medicines. Some other methods may help, such as nutrition, physical therapy, or deep breathing techniques. Also, chemotherapy, radiation therapy, or surgery may be used to shrink tumors that cause pain and other problems. Even though these methods are most often used to cure cancer, they're sometimes used to make people more comfortable.

**Emotional and coping.** Palliative care specialists can guide patients and families to the kind of help they need to deal with the emotions that come with cancer and its treatment. Depression, anxiety, and fear are only a few of the concerns that can be addressed in this way. Experts may offer counseling, find support groups, hold family meetings, or refer to mental health therapists.

**Social/financial.** Cancer patients may have financial and legal worries, insurance questions, job concerns, and questions about advance directives. For many people, the technical language and fine details of laws and legal forms are hard to understand. To ease the burden, the palliative care team may help coordinate the needed services. For example, the team may direct patients and families to resources that can help with financial counseling. The team may know where to get help with medical forms or legal advice. They may also help find local and national resources, such as those that can help with transportation or housing.

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**Spiritual.** When a person has cancer, patients and families often look more deeply for meaning in their lives. Some find the disease brings them deeper faith. Others may question their faith as they struggle to understand why cancer happened to them. Palliative care can offer help to explore beliefs and values so that a person can find a sense of peace or reach a point of acceptance

#### **Choosing Palliative Care**

Palliative care is given along with treatment for cancer. But when a patient reaches the point when treatment for the cancer is no longer working, palliative care becomes the main focus of care. It will continue to be given to help relieve the symptoms and emotional issues of cancer. Palliative care providers can help ease the transition to end-of-life care.

In many cases, advanced cancer happens after the person has had cancer for some time and treatment is no longer working. But for some people the cancer may already be advanced when they first find out they have it. In any case, symptoms such as pain and depression can almost always be treated.

It may be hard to think and talk about this. Everyone with cancer hopes that their cancer will be cured, but this is not always possible. When it becomes clear that there is nothing else that can be done to help a person live longer, the cancer care team can begin to make some predictions about end of life. Keep in mind that these are only educated guesses; no one can ever know for sure how long a person will live. Some people can live for years with advanced cancer.

Someone may still get cancer treatment, but the goal may no longer be to cure the cancer. At this time the purpose of care is often to control symptoms caused by the cancer so they can enjoy life and feel as good as they can. When symptoms get worse, the focus of care is to make the person comfortable.

Some people think that if cancer is in many parts of the body it is the same as advanced cancer. This is not always true. Usually when health care providers speak of advanced cancer, they are talking about cancers that cannot be cured (American Cancer Society.(20). Advanced Cancer. Retrieved October 8, 2015 from [www.cancer.org/treatment/understandingyourdiagnosis/advancedcancer/advanced-cancer-what-is](http://www.cancer.org/treatment/understandingyourdiagnosis/advancedcancer/advanced-cancer-what-is)). A

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person can have widespread cancer, but it can still be treatable and sometimes curable. Examples of this are testicular cancer, leukemias, and many lymphomas. In other cases, widespread cancer may not be curable.

On the other hand, cancer may not have spread to distant places but still be considered advanced. This may be because there is too much cancer to be removed, or it has caused major health problems. An example of this is pancreatic cancer. Or, some cancers that start in the brain are considered advanced because they cannot be cured. They can be life-threatening even if they don't spread.

#### **Can a family member receive palliative care?**

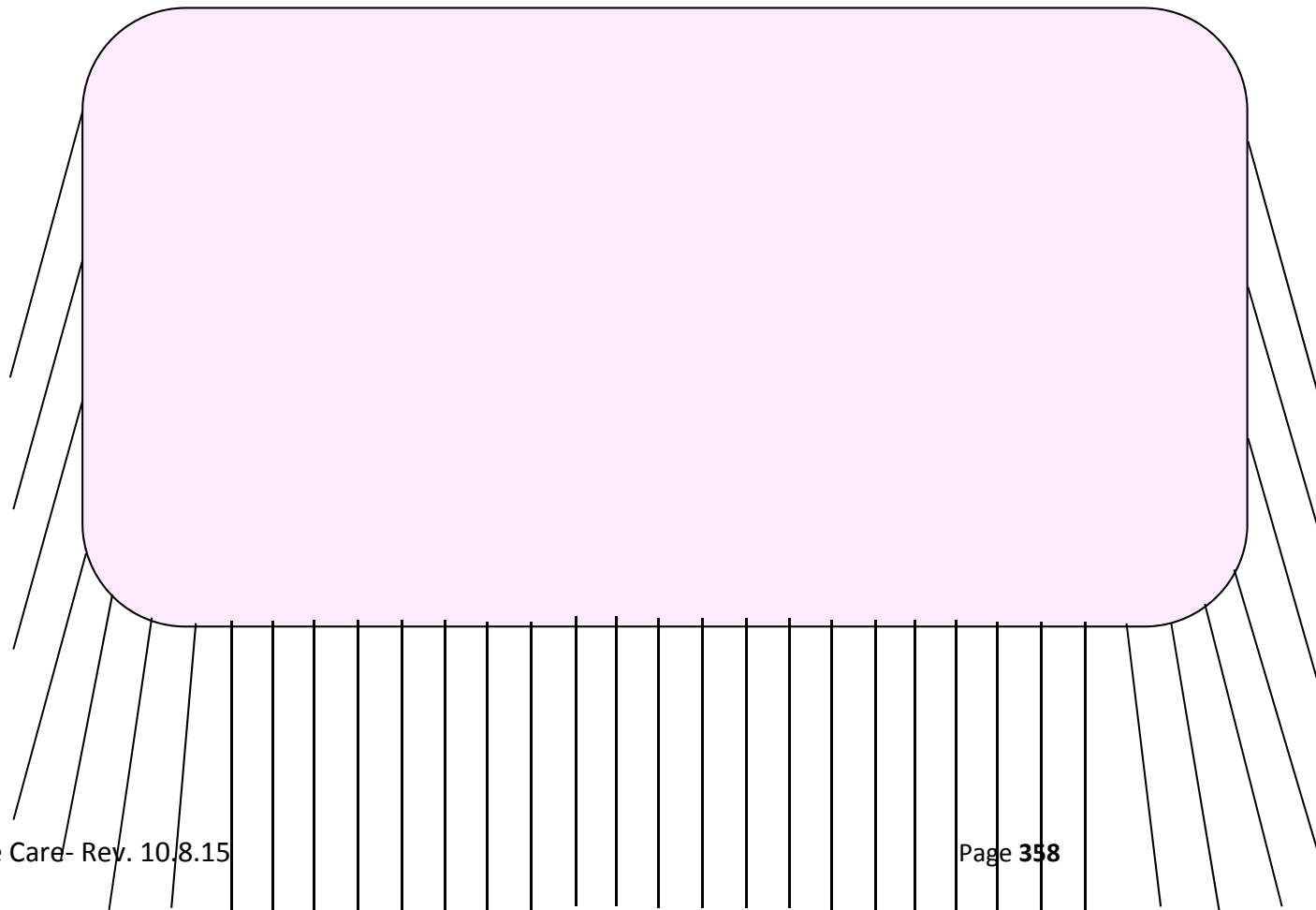
Family members and loved ones are an important part of cancer care. Like the patient, they have a number of changing needs. It's common for family members to be overwhelmed by the extra responsibilities placed upon them. Many find it hard to care for a loved one who is ill. They still have other obligations, such as work and caring for other family members. Other issues can add to this stress. A family member may feel unsure about how to help their loved one with medical problems and emotions such as worry and fear. There may not be enough social support for the patient or the family. These challenges can compromise the health of those who are trying to help. Palliative care can help families and friends cope with these issues and give them the support they need.

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**Activity**

Palliative care is “active total care for the body, mind and spirit of the person with cancer and their family.” – Definition from International Telehealth Palliative Care Symposium. Decorate the shawl below with words, symbols or pictures that show how palliative care can help someone.



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#### **Story of Hope**



*“I encourage people who are terminal with cancer to tell your family about it. To tell your children, to tell your aunties, your sisters, your mom and dad whomever. Give your family an opportunity to come and help you if they can. Sometimes they have strange reaction to that kind of information, but tell them.”*  
*CeCe Whitewolf, Confederated Tribes of Umatilla breast cancer survivor*

(Clark, R., (Producer) & Whitewolf, C. (Artist). (2007). *Survivor Video Vignettes: Let Others Help Uou*. [Web]. Retrieved from <http://www.natamcancer.org/vignettes/cc5-palliative.html>)

#### **Key Messages**

- The goal of palliative care is to support the best quality of life for the person with cancer and their family. Accepting palliative care does not mean someone is giving up, only that they wish to have a good quality of life.
- People have the right to decide what types of treatment they want, and they may still choose to have palliative treatment.
- Make a note of all cancer-related pain and concerns to discuss with the health care provider.



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Chapter 3: Addressing Cancer Pain as a part of Palliative  
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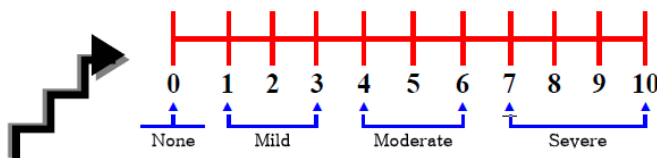
## Addressing Cancer Pain as Part of Palliative Care

Group Discussion			
	True	False	Not Sure
1. Health care providers cannot assess cancer pain.			
2. Everyone with cancer experiences pain.			
3. Cancer pain can almost always be relieved or lessened.			

Not all people with cancer will experience pain. But some will need to have their pain managed by their health care provider. It is important to talk with a health care provider about any pain and find the best way to manage it. It may take a few tries to get pain under control, so report back to the health care provider on how well the pain treatment is working. A person's pain may change over time, so the medicines and methods may need to change, too.

Health care providers need enough information to correctly assess the level of pain. Many providers ask people to rate their pain on a scale from zero to 10. Zero means that you are experiencing no pain, and 10 means that a person is in the highest level of discomfort from pain.

0 – 10 Numeric Rating Scale (page 1 of 1)



A health care provider may also use this faces pain scale to illustrate the level of pain:

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### **Facts about Cancer Pain Treatment**

Uncontrolled pain can keep you from doing things that are important to you and your family. Cancer pain can almost always be relieved or lessened. There are many medicines and methods that can be used to control cancer pain. You should expect your health care team to work with you to keep you as comfortable as possible. But no one health care provider can know everything about all medical problems, and sometimes pain is a subject they don't know as much about. Even though a lot of progress has been made, some health care providers do not know the best ways to treat cancer pain.

If you are in pain and your health care provider has nothing more to offer, ask to see a pain specialist or have your health care provider consult with a pain specialist. Pain specialists may be oncologists, anesthesiologists, neurologists, neurosurgeons, other health care providers, nurses, or pharmacists. A pain control team may also include psychologists and social workers.

If you have trouble finding a pain program or pain specialist, contact a cancer center, a hospice, or the oncology department of your local hospital or medical center. They should be able to recommend someone to you.

#### **1. Controlling your cancer pain is part of your cancer treatment.**

Your health care provider wants and needs to hear about what works for your pain and what does not. Knowing about the pain will help your health care provider know more about how the cancer and the treatment are affecting your body. Talking about pain will not distract your health care provider from treating the cancer.

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#### **2. Keeping pain from starting and keeping it from getting worse are the best ways to control it.**

Pain is best relieved when treated early. You may hear some people refer to this as “staying on top of the pain.” Do not try to hold off as long as possible between doses. Pain may get worse if you wait. Then it may take longer, or you may need larger doses, for your medicine to give you relief.

#### **3. You have a right to ask for pain relief.**

Talking about your pain is not a sign of weakness. Not everyone feels pain in the same way. There is no need to “tough it out” or be “brave” if you seem to have more pain than other people with the same kind of cancer. In fact, as soon as you have any pain you should speak up. Remember, it is easier to control pain right when it starts rather than waiting until it becomes severe.

#### **4. People who take cancer pain medicines the way the health care provider tells them to rarely become addicted to them.**

Addiction is a common fear of people taking pain medicine. Such fear may even keep people from taking the medicine. Or it may cause family members to encourage you to hold off as long as you can between doses.

Addiction is defined as uncontrollable drug craving, seeking, and continued use of a substance even though it causes serious problems for the person. When *opioids* (also known as narcotics) – the strongest pain relievers available – are taken for pain, they rarely cause addiction as defined here. When you are ready to stop taking opioids, the health care provider will lower the amount of medicine you are taking over a few days or weeks. By the time you stop using it completely, your body has had time to adjust. Talk to your health care provider, nurse, or pharmacist about how to take pain medicines safely and about any concerns you have about addiction.

#### **5. Most people do not get “high” or lose control when they take cancer pain medicines the way they are told to.**

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Some pain medicines can cause you to feel sleepy when you first start taking them. This feeling usually goes away within a few days. Sometimes you become drowsy because now that the pain is under control, you are able to catch up on the much-needed sleep you missed when you were in pain. Sometimes, people get dizzy or feel confused when they take pain medicines. Tell your health care provider or nurse if this happens to you. Changing your dose or type of medicine can often solve these problems.

#### **6. Side effects from pain medicines can be managed and often even prevented.**

Some medicines can cause nausea and vomiting, itching, constipation, or drowsiness. Your health care provider or nurse can help you manage these side effects. But some of these problems go away after a few days of taking the medicine. And many side effects can be managed by changing the medicine, the dose, or the times when the medicine is taken. Others, like constipation, can often be prevented with stool softeners and other measures.

#### **7. Your body does not become immune to pain medicine.**

Pain should be treated early, and stronger medicines should not be saved for later. It is important to take whatever medicine is needed when it is needed. Your body may get used to the medicine you are taking so the medicine may not relieve the pain as well as it once did. This is called *tolerance*. Tolerance is seldom a problem with cancer pain treatment because your health care provider can increase the amount of medicine you are taking or add other medicines. Some people are alarmed by this because they are afraid it means they are addicted, but it is not the same thing. It only means that your body has learned to adjust to the drug in your system over time. It is important to stick with the doses your health care provider prescribes, and be sure that your provider knows all the medicines you are taking. Some pain medicines (even those that you can buy without a prescription) can cause more serious or permanent effects if too much is taken.

When pain is not relieved, you may feel:

- Tired

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- Depressed
- Angry
- Worried
- Lonely
- Stressed

When cancer pain is relieved, you are more able to:

- Enjoy being active.
- Sleep better.
- Enjoy family and friends.
- Eat better.
- Enjoy sexual intimacy.
- Prevent depression.

#### **Key Messages**

- Pain management is an important part of a person's care.
- If a person has pain, they need to talk to their health care provider to find the best ways to manage it. It may take a few tries to get pain under control, so talk with your provider about how well your pain medicines are working.
- Make a note of all cancer-related pain and concerns to discuss with your health care provider.



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**Chapter 4: Home Care**



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## Home Care

<b>Group Discussion</b>			
	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.

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

## ***Circle Of Life: Cancer Education and Wellness***

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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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## Wellness along the Cancer Journey:

### Palliative Care

Revised October 2015

## Chapter 5: Behavior Change Questions



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**Behavioral Change Questions**

<p><b>First, select what you did or thought before you did before you participated in this session.</b></p> <p><b>Second, select what you think or will do now that you have participated in this session.</b></p>	Before this I ...					After this I ...				
	None ←————→ A Lot					None ←————→ A Lot				
	1	2	3	4	5	1	2	3	4	5
How much do you know about palliative care?										
How much do you know about the goals of palliative care?										
How much do you know about the ways health care providers assess pain?										
How much do you know about hospice care?										
How much do you know about home care?										

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**Palliative Care**  
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Chapter 6: Knowledge Questions





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**Knowledge Questions**

Palliative Care Knowledge Questions	True	False	Not Sure
1. Health care providers cannot assess cancer pain.			
2. Everyone with cancer experiences pain.			
3. Cancer pain can almost always be relieved or lessened			
4. Palliative care is only given at the end of life.			
5. The goal of palliative is to only treat the physical side effects of cancer.			
6. Family members can also be helped by palliative care.			
7. Hospice care is the same as home care.			
8. Home care is care given outside of the hospitals and medical visits.			

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## Wellness along the Cancer Journey:

### Palliative Care

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## Chapter 7: Appendices



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**Appendices**

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**Appendix A: Additional Palliative Care Resources**

Along with the American Cancer Society, other sources of information and support include:

**Get Palliative Care** (offered by the Center to Advance Palliative Care)

This website provides palliative care information for people coping with serious illnesses. The site includes a Palliative Care Provider Directory of Hospitals, a definition of palliative care, and detailed descriptions of what palliative care does and how to get it. It also provides an interactive questionnaire to help you decide whether palliative care might be helpful for you or a loved one.

Website: [getpalliativecare.org](http://getpalliativecare.org)

**American Academy of Pain Management**

This group credentials multidisciplinary pain practitioners.

Website: [aapainmanage.org](http://aapainmanage.org)

**The American Pain Society**

The American Pain Society is a multidisciplinary organization of basic and clinical scientists, practicing clinicians, policy analysts, and others. The mission of the American Pain Society is to advance pain-related research, education, treatment and professional practice.

Phone: 847-375-4715

Website: [ampainsoc.org](http://ampainsoc.org)

**Beth Israel Medical Center: Department of Pain Management and Palliative Care**

The Department of Pain Medicine and Palliative Care is dedicated to providing comprehensive care of the highest quality in pain management and palliative care, and advancing the educational and research aims of these disciplines.

Website: [www.stoppain.org](http://www.stoppain.org)

**City of Hope Pain/Palliative Care Resource Center (COHPPRC)**

Phone: 626-256-4673, extension 63829

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Website: [prc.coh.org](http://prc.coh.org)

Has information on palliative care and pain management, as well as educational programs on death and dying

#### **Family Caregiver Alliance**

Toll-free number: 1-800-445-8106

Website: [caregiver.org](http://caregiver.org)

Provides information and resources on long-term caregiving. A search feature on their website helps a person find caregiver support programs in each of the 50 states and the District of Columbia

#### **Hospice Foundation of America (HFA)**

Toll-free number: 1-800-854-3402

Website: [hospicefoundation.org](http://hospicefoundation.org)

Offers education and information about hospice care. Lists hospices by region, which is available at [www.hospicedirectory.org](http://www.hospicedirectory.org)

#### **Hospice Net**

Website: [hospicenet.org](http://hospicenet.org)

Provides information and support to patients facing life-threatening illnesses and to their families and friends; also can help find a local hospice

#### **Hospice Education Institute**

Toll-free number: 1-800-331-1620

Website: [hospiceworld.org](http://hospiceworld.org)

Offers information about caring for the dying and those who have lost a loved one. Has a directory of hospice and palliative care programs in the United States; and offers general information about good hospice care.

#### **National Family Caregivers Association (NFCA)**

Toll-free number: 1-800-896-3650

Website: [thefamilycaregiver.org](http://thefamilycaregiver.org)

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Quarterly newsletter offers can-do advice, helpful resources and stories for family caregivers. It also offers a bereavement kit for when members lose their loved one to help them deal with their loss and move on with their lives

**National Hospice and Palliative Care Organization (NHPCO)**

Toll-free number: 1-800-658-8898; in Spanish 1-877-658-8896

Web site: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

Provides information about hospice programs in your area; also offers general information about hospice, including frequently asked questions