

Palliative Care, Diagnosis and Working Together

This section of the resource toolkit contains a working definition of palliative care from the perspective of First Nations, Inuit and Métis people. It contains additional definitions of palliative care from a public health perspective.

It also provides information related to cancer including metastatic and advanced cancer, and information tools for coping and communicating with the health care system to ensure that diagnosis and options are understood.

What is Palliative Care?

A Working Definition of Palliative Care for First Nations, Inuit and Métis People

To develop this resource toolkit on palliative care, Cancer Care Ontario sponsored an initiative in 2013-14 involving focus group discussions with First Nations, Inuit and Metis community participants from across Ontario. Through this process, the following working definition of palliative care emerged:

To First Nations, Inuit and Métis people, palliative care means “comfort care”:

- *Kind, compassionate care that is given with understanding and respect*
- *Care that relieves a person’s pain and symptoms for the best quality of life*
- *Care that honours a person’s spiritual beliefs, traditions and customs*
- *Care for the whole person and support for the whole family*

Other Ways of Defining Palliative Care

Palliative care has also been defined by many organizations. The Cancer Care Ontario (CCO) Palliative Strategy¹ lists several definitions of palliative care which also speak to comfort and quality of life:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization).

Palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved (Canadian Hospice/Palliative Care Association).

Palliative care refers to both a program and a concept of care based on the provision of comfort. It is designed for individuals who are living with, or dying from, a progressive life threatening illness. The program enhances quality of life through pain and symptom control and provides emotional and spiritual support for both patients and families. Compassionate and specialized care is provided with specialized knowledge and skills (Canadian Cancer Society).

Cancer Diagnosis and Communications

Organizations such as the Canadian Cancer Society and Cancer Care Ontario have produced extensive information about cancer including diagnosis, staging and treatment. Some general information resources from these and other sources are provided in this section of the toolkit.

Checklists for communicating with health professionals about cancer and palliative care are also listed below.

What is Cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy. But sometimes the instructions get mixed up, causing the cells to form

lumps or tumours, or spread through the bloodstream and lymphatic system to other parts of the body.

Tumours can be either benign (non-cancerous) or malignant (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening.

Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. Cancer cells that spread to other parts of the body are called metastases.

The first sign that a malignant tumour has spread (metastasized) is often swelling of nearby lymph nodes, but cancer can metastasize to almost any part of the body. It is important to find malignant tumours as early as possible.

Cancers are named after the part of the body where they start. For example, cancer that starts in the bladder but spreads to the lung is called bladder cancer with lung metastases².

Metastatic Cancer Overview

Cancer can start in any organ or tissue in the body. A *primary* cancer or tumour is the first, original tumour that develops in the body. *Metastatic* cancer occurs when cancer spreads from its original location (primary tumour) to a new part of the body.

How cancer spreads

As cancer cells divide, they can invade and grow directly into surrounding tissue or structures (direct extension). But, they can also break off from the original (primary) tumour and enter the bloodstream or lymphatic system. If the cancer cells are not detected by the immune system, which helps defend the body against infection and disease, they can be carried by the blood and lymph to form a new tumour in another area of the body. A tumour in a new location must develop its own blood supply (a process called angiogenesis) to survive and grow.

Where cancer can spread

Localized cancer means the cancer is confined to the original site. Regional spread means the cancer has either grown into surrounding tissues or nearby lymph nodes. The term *metastatic cancer* is usually only used for cancer that has spread to distant organs or distant lymph nodes (distant metastasis).

Cancer can spread almost anywhere in the body. The most common sites of metastases are in the bones, the brain, the liver and the lungs.

Why cancers spread

All cancers have the potential to spread. Whether metastases will develop depends on many factors:

- *The type of cancer*
 - Some types of cancer tend to spread to certain parts of the body.
 - Breast cancer most often spreads to the bones, liver, lung or brain.
 - Colorectal cancer tends to spread to the liver.
 - Lung cancer often spreads to the brain, bones or liver.
 - Prostate cancer tends to spread to the bones.
- *The grade of the cancer*
 - Low-grade cancer cells are less aggressive and are less likely to metastasize.
 - High-grade cancer cells are more aggressive and are more likely to metastasize.
- *The length of time the cancer has been present*
 - The risk of metastasis increases the longer a tumour is in the body.
- *The cancer cells' ability to create a blood supply in a new location*
 - A cancerous tumour needs to set up a blood supply to grow.
- *The location of the primary tumour*
 - Each type of cancer has a particular way that it spreads. Many metastases develop in the first area of blood vessels that cancer cells come to after leaving the primary tumour. After leaving the primary tumour, the lungs are one of the first places metastatic cells can be carried to by the bloodstream. This may explain why metastases form in the lungs.

Signs and Symptoms

Some people may have no or few symptoms related to their metastasis. Therefore, a metastatic cancer may only be discovered during a routine examination or test. Symptoms of metastatic cancer will depend on the particular location and size of the metastasis.

- Bone metastases may cause pain or a break in the bone (fracture). It can also put pressure on a nerve or the spinal cord, which can cause numbness or muscle weakness.
- Brain metastases may cause headaches, problems with balance or coordination, or seizures.
- Liver metastases may cause abdominal pain, abdominal swelling or jaundice.
- Lung metastases may cause cough or shortness of breath.

Getting regular check-ups and reporting new symptoms are the best ways to detect metastatic cancer early. In some cases, the metastatic tumour is found before the primary tumour because it produces symptoms before the primary tumour does.

Diagnosis

Diagnostic tests will be done if the signs and symptoms of metastatic cancer are present, if the result of a follow-up test is abnormal or if the doctor suspects a metastasis. The types of tests done will depend on the area of the body where doctors suspect the cancer has spread. Tests may include:

- complete physical examination
- laboratory tests
 - In some cases, tumour marker tests are done. Tumour markers are substances – usually proteins – that may indicate cancer is present. Tumour markers for metastatic cancer are usually measured by doing blood tests.
- imaging tests
 - A bone scan is done to see if cancer has spread to the bone.
 - A computed tomography (CT) scan of the head is done to see if cancer has spread to the brain.
 - An ultrasound or CT scan of the abdomen may be done to see if cancer has spread to the liver.
 - An x-ray or CT scan of the chest may be done to see if cancer has spread to the lung.
 - In some cancers, a positron emission tomography (PET) scan can detect small amounts of cancer in different parts of the body where the cancer may have spread.
- biopsy
 - To find out if a tumour is primary or metastatic, some of the cancerous tissue may be removed and examined under a microscope. This will show if the cancer cells developed in that area or if they have spread from another area of the body.
 - Sometimes a metastatic tumour is found, but doctors do not know where the cancer started (primary site). This is called cancer of unknown primary.

Additional tests may be done to determine if a metastasis is present, where it is in the body and how extensive it is.

Staging

Staging is a way of classifying a cancer based on the extent of cancer in the body. When cancer has spread beyond the primary tumour location or region (Stage I- III) to distant organs or sites (Stage IV), it is said to have metastasized. Metastatic cancer can be found before or at the same time as the primary tumour. It can also develop after the primary cancer is diagnosed.

Cancer cells frequently spread to lymph nodes near the primary tumour. These are called regional lymph nodes. Cancer that spreads to lymph nodes far from the primary tumour (distant lymph nodes) is usually called metastatic disease.

Recurrence means that cancer has come back after it has been treated. Cancer can recur several weeks, months or years after treatment. If someone has been treated for cancer and doctors find a new tumour in a different location, it is usually a metastasis of the original cancer. It is possible to develop a new primary tumour unrelated to the original cancer, but this is very unusual.

Prognosis and Survival

People with metastatic cancer should talk to their doctor about their prognosis. Prognosis depends on many factors. The doctor will put the following information together with survival statistics to arrive at a prognosis for each individual:

- a person's medical history
- type of primary cancer
- extent of metastasis
- characteristics of the cancer
- treatments chosen
- response to treatment

The doctor is the most qualified person to answer questions about what the future might hold for someone with metastatic cancer.

Treatment

Each person with metastatic cancer will have a treatment plan designed for them by their healthcare team. The team will recommend treatment options based on the specific characteristics of the cancer and the unique needs of the person. Treatment of metastatic cancer depends on many factors, including:

- where the cancer first started (primary site)
- where the cancer has spread – the number, size and location of metastases
- the person’s age and overall health
- previous treatment

Treatment for metastatic cancer is often aimed at controlling symptoms and slowing the progression of the cancer.

A treatment plan for metastatic cancer may include one or more of the following:

- chemotherapy
- radiation therapy
- hormonal therapy
- biological therapy
- surgery

The person with metastatic cancer will have regular follow-up visits to check how they respond to treatment or to see how well their symptoms are being controlled.

Supportive Care

A cancer diagnosis can lead to many challenges for people with cancer and their families. Each person's experience will be different because their cancer, treatment and recovery are different. A person with metastatic cancer may have concerns about:

- pain
- symptoms of advanced cancer
- the future

There are many treatments and strategies that can help people with metastatic cancer manage their symptoms and improve their quality of life.

Clinical Trials

Canada is an international leader in conducting research studies called clinical trials. A person with metastatic cancer may be offered the opportunity to participate in a clinical trial. Clinical trials for metastatic cancer are often included in studies being done for a particular type of primary cancer. The primary type of cancer is often the best place to first look for metastatic cancer clinical trials. However, there may also be trials that study certain types of metastatic cancer³.

Advanced Cancer

A diagnosis of advanced cancer can be very hard to understand and accept. If you or someone you love has been diagnosed with advanced cancer, you may feel overwhelmed, like you can't take it all in or that it's just a bad dream. You might not be sure that you understand what the doctor meant. Advanced cancer is defined as *cancer that is unlikely to be cured*. Healthcare professionals may also use the terms secondary, metastatic, terminal or progressive cancer to describe it.

Most people living with advanced cancer experience a wide range of feelings and emotions as they come to accept the diagnosis. These feelings can be overwhelming at first, but most become more manageable as you get used to the diagnosis and start to make plans and decisions.

Shock and disbelief – It's difficult to hear that cancer can't be cured, and you may not want to believe what you've been told. Many people say they feel numb or like they're walking around in a fog.

Anger – It's normal to be angry at the person who has told you the news or angry that the treatment hasn't worked. Your anger could be directed anywhere, from your family and friends to your god or fate.

Sadness, loneliness and isolation – Finding out you or someone you love has advanced cancer usually leads to a deep sense of loss. While family and friends may want to be close to you, you may not feel like you want to be around people as you come to terms with the diagnosis. You may feel isolated, as if no one could possibly understand what you're going through.

Guilt – Some people diagnosed with cancer feel guilty for leaving loved ones behind or causing sorrow. Some people worry that they should have gone to the doctor earlier or fought harder against the disease. Loved ones may feel guilty that they haven't done enough.

Fear – It's normal to feel very scared of advanced cancer. People with advanced cancer may fear being in pain and suffering, being left alone or dying alone, becoming a burden, losing control of the body and needing others' help, losing dignity, the unknown and the future, or leaving loved ones behind.

Moving forward

Accepting the diagnosis and adjusting to life with advanced cancer often takes time. Acceptance doesn't mean giving up. Rather, acceptance allows you to take control of your life and focus on what's most important to you. Many people find that as they become more accepting of the situation, some positive feelings help to balance the difficult emotions.

As you move forward, you may connect more deeply with people in your life, spend more time with them and tell them how important they are to you. Some people go back to visit places that had special meaning in their life or go on a trip they've wanted to take for many years. You may try to talk to or visit old friends that you have lost contact with over the years. You may want to heal a relationship that has been difficult or awkward, clear up past arguments or misunderstandings and talk about hurt feelings to find peace with someone again.

Some people find it helpful to do a life review, which means looking back on your life and perhaps talking about it with another person. This can be an important part of remembering the many ways in which your life has meaning and value. Life reviews can be hard work. They take honest and deep reflection on who you are and how you came to be that person.

For some people, being diagnosed with cancer leads to spiritual discovery. This deeply personal process may continue or change when you have advanced cancer.

There is no way of knowing or predicting how long someone will live with advanced cancer. Some people may live much longer than expected, while others may die sooner than expected. Doctors may be able to guess at a timeline based on what they know about a person and the type of cancer, but it's not an exact science⁴.

Cancer Among First Nations, Inuit and Métis People: Overview

There is a significant disparity between the health status of Ontario's First Nations, Inuit and Métis people and the general population. Evidence of this is in the growing incidence of cancer and the lower First Nations, Inuit and Métis survival rates compared to other people in Ontario.

First Nations

The work of Dr. Loraine Marrett at Cancer Care Ontario looked at the incidence of cancer in the First Nations population and survival data for the period 1968 to 2001. The overall cancer incidence rate in First Nations people, while still well below the rate of the general population, was found to be rising more quickly and nearly doubled during this period. New cases of

colorectal cancer among First Nations people had tripled and new cases of breast cancer among First Nations women had almost doubled during this time. For the major cancers (colorectal, lung, prostate, breast and cervical cancers), survival was found to be significantly worse in First Nations people compared to the general population in Ontario⁵.

The First Nations Regional Health Survey for 2008-10 found that out of 1,500 First Nations adult respondents in Ontario, 2.5% had been diagnosed with cancer, and this rate increased to 6.9% for those aged 60 and over⁶.

Inuit

Cancer is the second leading cause of death among Inuit. Incidence rates are increasing, especially in rates for preventable cancers such as lung cancer. Compared to the general population of Canada, Inuit have a higher incidence of lung, liver, oesophageal, nasopharyngeal, and salivary cancer.

A circumpolar Inuit cancer review by Dr. Kue Young found that from 1969 to 2003, lung cancer rates for Inuit men and women in Canada were the highest in the world, and these rates were on the rise. Colorectal cancer rates for Inuit in Canada had also risen sharply⁷.

Métis

The Métis Nation of Ontario and the Institute for Clinical Evaluative Sciences found that from 2005 to 2007, for people aged 65 years and older the rate of cancer diagnosis was higher in the Métis than in the general Ontario population, with the gap being greatest among people 75 years and older (rates 1.4 times higher in the Métis).

The top four cancers diagnosed among the Métis were (in order) lung, prostate, colorectal and breast cancer, compared to (in order) prostate, breast, colorectal and lung in the general Ontario population⁸.

Cancer: Growing Concern among Canada's First Peoples

Having adopted the lifestyle practices of modern civilization, and having been exposed to industrial toxins in the food supply and environment the incidence of cancer has become increasingly common over the decades for Canada's First Peoples, and it continues to rise in incidence. This relentless increase in cancer is accelerating, while survival following cancer diagnosis has been poorer for Aboriginal peoples than for the general population. Thus we find today that cancer has become a major health concern and priority among Aboriginal peoples in Canada. A study of First Nations throughout the United States, reveals that cancer is the second

leading cause of death among American Indians and Alaska natives over the age of 45. Not unlike Canada's first peoples, cancer rates among America Indians and Alaska Natives are rising, and American Indians have the poorest survival rate from cancer of any minority population in the U.S.⁹.

Getting Quality Care as a Cancer Patient

As a cancer patient, or as the guardian or advocate of a cancer patient, you are entitled to ask questions, be informed, and take part in decisions about your or your loved one's care, including:

- Expressing any concerns about treatment
- Asking for information in clear, understandable language
- Asking for a second opinion without fear that treatment will be affected
- Exploring treatment options in other provinces or countries
- Deciding whether students or researchers are present
- Being informed and making decisions about alternative or complementary treatments
- Refusing any course of treatment
- Seeking legal advice about a complaint if necessary

You can enhance the quality of care by providing your healthcare team with as much information as possible in the following areas:

- Past and present health concerns, hospital stays, medications, etc., including information about home, social life, school, or work that might influence care
- Any difficulties you may have in complying with treatment schedules and appointments
- Any difficulties you may have in affording treatment or related expenses
- Any legal issues or documents that relate to care or decision-making e.g. power of attorney or court orders
- The need for translation or interpretation services
- Emotional distress, isolation, or depression, and the need for social or peer support¹⁰

Appointment Checklist

Here is a checklist of things to bring with you to your appointments:

- ✓ Cash for travel expenses and parking
- ✓ Someone to wait with you and support you during your visit
- ✓ Any patient orientation information you might have been given
- ✓ Your Ontario health card
- ✓ The name, address and phone number of your family doctor
- ✓ Your drug benefit plan identification card if applicable
- ✓ The current medications you are taking in their original containers
- ✓ Any vitamins, minerals, herbal supplements you are taking, in their original containers
- ✓ A list of any allergies and sensitivities
- ✓ A notebook and pen to record information
- ✓ A list of questions you may have for the doctor or nurse
- ✓ A drink and/or snack from home, or cash for purchasing snacks
- ✓ Something to help you pass the time while you wait (a book, knitting, etc.)¹¹

Tools for Coping: Questions to Ask Your Doctor About Your Cancer

Being told you have cancer can be scary and stressful. You probably have a lot of questions and concerns. Learning about the disease, how it's treated, and how this information might apply to you is a lot to do on your own. You might need some help.

Your local community health care worker, Aboriginal Patient Navigator, regional cancer centre or other sources can give you general information about the cancer and its treatment, but your doctor is the best source of information about your situation.

It is important for you to be able to talk openly with your cancer care team. They want to answer all of your questions, no matter how minor they might seem to you. But it helps if you know what to ask.

Here are some questions you can use to help you better understand your cancer and your options. Don't be afraid to take notes and tell the doctors or nurses when you don't understand what they're saying.

The questions below are grouped by where you are in the process of cancer treatment. Not all of these questions will apply to you, but they should help get you started.

Questions to ask when you're told you have cancer

1. Exactly what kind of cancer do I have?
2. How do I get a copy of my pathology report?
3. Where is the cancer located?
4. Has the cancer spread beyond where it started?
5. What's the cancer's stage? What does that mean?
6. How does this affect my treatment options and long-term outcome (prognosis)?
7. What are my chances of survival, based on my cancer as you see it?
8. How much experience do you have treating this type of cancer?
9. Will I need other tests before we can decide on treatment?
10. What are my treatment choices?
11. What treatment do you recommend and why?
12. What's the goal of my treatment?
13. Should I think about genetic testing?
14. Should I get a second opinion? How do I do that?
15. Should I think about taking part in a clinical trial?

Questions to ask when deciding on a treatment plan

1. What are the chances the cancer will come back after this treatment?
2. What would we do if the treatment doesn't work or if the cancer comes back?
3. Will I be able to have children after treatment?
4. How much will I have to pay for treatment? Will my insurance cover any of it?
5. How long will treatment last? What will it involve?
6. Where will treatment be done?
7. What risks and side effects should I expect?
8. What can I do to reduce the side effects of the treatment?
9. How will treatment affect my daily activities?
10. Will I be able to work during treatment?
11. Will I lose my hair? If so, what can I do about it?
12. Will the treatment hurt? Will I have any scars?

Questions to ask before treatment

1. What should I do to get ready for treatment?
2. Will I need blood transfusions?
3. Should I change what I eat or make other lifestyle changes?

During treatment

Once you have decided on treatment, you'll need to know what to expect and what to look for. All of these questions may not apply to you, but asking the ones that do may be helpful.

1. How will we know if the treatment is working?
2. Is there anything I can do to help manage side effects?

3. What symptoms or side effects should I tell you about right away?
4. How can I reach you on nights, holidays, or weekends?
5. Do I need to change what I eat during treatment?
6. Are there any limits on what I can do?
7. What kind of exercise should I do, and how often?
8. Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?
9. Will I need special tests, such as imaging scans or blood tests, and how often?

After treatment

1. Do I need a special diet after treatment?
2. Are there any limits on what I can do?
3. What kind of exercise should I do now?
4. What type of follow-up will I need after treatment?
5. How often will I need to have follow-up exams and imaging tests?
6. What blood tests will I need?
7. How will I know if the cancer has come back? What should I watch for?
8. What are my options if the cancer comes back¹²?

Talking to Children About Cancer

Children may be able to cope better if you openly discuss your cancer in ways that are appropriate to their age.

Being open with children

Parents worry that telling their kids — especially very young ones — about their cancer will cause them unnecessary anxiety or pain. Some think that their children won't understand or be able to cope. Although this reaction comes from a natural urge to protect them, it may ultimately do more harm than good.

Children can be very perceptive — they may pick up on clues that something is wrong. They may overhear conversations or be asked questions by family and friends that they are not prepared to answer.

However, by including your children in discussions and decisions about issues related to your illness, you will continue to foster their trust and emotional growth, no matter their age. It is up to each person with cancer to decide how much they tell their children about their illness, but keep in mind that openness can often be beneficial.

What should be shared?

Children of different ages need different levels of information. Deciding how and what to tell them is the tricky part. The key is to find the language and level of detail that is appropriate for your child — what works for one may not for another. You may find that your children react very differently from one another depending not only on their ages, but also on their gender and personalities.

Also, it's important to remember that discussing issues related to your cancer is an ongoing process. As you receive treatment, experience related side effects and learn to adapt to the new realities of your life, your children need to be informed and reassured on a regular basis.

Basic information that all kids need to know:

- The type of cancer
- Where it is in the body
- You will receive treatment for the cancer to try to cure it
- These treatments may make you sick or tired for a little while
- Let them know ahead of time about any changes to your appearance that may occur because of treatment (reassure them that it's normal and only temporary)
- Cancer cannot be "caught" like a cold – it's not contagious

Inherited Risk and Cancer

Some cancers have a risk that can be inherited. This is called a genetic predisposition. If your children ask if they will inherit cancer, here are some important ideas to tell them:

- Not all cancers can be passed on or are hereditary
- Even when a cancer can be passed on, it doesn't mean you will definitely get cancer
- There are other factors that contribute to getting cancer, including the environment and how we take care of our health
- If the family has an inherited risk, doctors can watch for it very closely at regular check-ups

In an age-appropriate way, reassure your children

- They will be taken care of and loved no matter what happens
- You love them and that anything they do to help will make you happy
- It's good to ask questions and to talk about your illness
- It's okay to feel scared, angry or sad
- They should tell you about how they feel so you can help them
- Your cancer was not caused by anything they did or thought
- It's good to hug and kiss you, cancer can't be caught from someone
- Treatments are very successful now and many people survive cancer

Maintain routines as much as possible

Children thrive on routine and can get frustrated when unexpected changes occur in their daily lives. Tell your children in advance of changes that are about to happen. Let them know that these changes are temporary and that things will get back to normal after.

To help keep your children's routine as normal as possible, ask family and friends for a little help. For example, instead of cancelling activities your kids are involved in like sports, lessons, or regular outings, make alternative arrangements for pick-up and drop-off.

Ask a friend to cook a meal for your family, arrange a sleepover at a friend's house, or ask a trusted friend to take your child along for a fun day-trip.

A certain level of disruption in your children's daily activities may be difficult to avoid. Try to involve your children in decisions that will affect how they spend their time. For example, instead of telling your child to take on a new chore, give them options or ask them to suggest an additional task they could do to help out.

Be honest with what you can and cannot do

As you go through various treatments for your cancer, you may experience a range of side effects. This may affect your energy level and your ability to perform daily activities. For example, if you are experiencing fatigue, tell your children how you feel and try to share in activities that you can manage.

- Try to focus on the most important activities, such as the ones that you know bring comfort to your child like reading stories, watching a funny movie together, or grabbing ice cream
- Try to find new ways to connect - the more time you spend with your children, the more likely they are to open up to you about how they feel

Watch for signs your child is having difficulties coping

It's a good idea to be proactive about informing and supporting your children. Kids may not want to ask many questions, especially the difficult ones. Waiting until they act out their frustrations can make it harder to address.

- As much as possible, stay on top of their progress at school
- Let teachers or other professionals at your child's school know that your child may be going through a tough period (they don't have to know the details of your illness, but they can let you know if your child is having more difficulty with class work or classmates)
- If you feel like your kids are withdrawing from you or from their normal activities, seek help from trusted family members and friends

- You may also want to consider seeking help through counselling that may be available at your hospital or cancer center that is specifically geared towards helping children

Questions about death

You should be prepared for your children asking you about death. If your children are older, this may be one of the first questions they ask you.

- Be honest about what doctors think your prognosis is
- Tell them that while you can't guarantee anything, you are receiving good care and you will fight as hard as you can to get better
- Let them know that treatments are always improving and that not everyone dies from cancer
- Reassure them that if your cancer gets more serious and death becomes a possibility, you will let them know
- Encourage them to focus on living life fully and enjoying every day as much as they can
- For very young children, use the phrase “very, very, very sick” to help them tell the difference between cancer and non-life threatening illnesses¹³

Palliative Care in Cancer

Palliative care addresses the emotional, physical, practical, and spiritual issues of cancer. Family members may also receive palliative care. Research shows that palliative care improves the quality of life of patients and family members, as well as the physical and emotional symptoms of cancer and its treatment.

1. What is palliative care?

Palliative care is care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. 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, in addition to the related psychological, social, and spiritual problems. The goal is not to cure. Palliative care is also called *comfort care*, *supportive care*, and *symptom management*.

2. When is palliative care used in cancer care?

Palliative care is given throughout a patient's experience with cancer. It should begin at diagnosis and continue through treatment, follow-up care, and the end of life.

3. Who gives palliative care?

Although any medical professional may provide palliative care by addressing the side effects and emotional issues of cancer, some have a particular focus on this type of care. A palliative care specialist is a health professional who specializes in treating the symptoms, side effects, and emotional problems experienced by patients. The goal is to maintain the best possible quality of life.

Often, palliative care specialists work as part of a multidisciplinary team to coordinate care. This palliative care team may consist of doctors, nurses, registered dietitians, pharmacists, and social workers. Many teams include psychologists or a hospital chaplain as well. Palliative care specialists may also make recommendations to primary care physicians about the management of pain and other symptoms. People do not give up their primary care physician to receive palliative care.

4. If a person accepts palliative care, does it mean he or she won't get cancer treatment?

No. Palliative care is given in addition to cancer treatment. However, when a patient reaches a point at which treatment to destroy the cancer is no longer warranted, palliative care becomes the total focus of care. It will continue to be given to alleviate the symptoms and emotional issues of cancer. Palliative care providers can help ease the transition to end-of-life care.

5. What is the difference between palliative care and hospice?

Although hospice care has the same principles of comfort and support, palliative care is offered earlier in the disease process. As noted above, a person's cancer treatment continues to be administered and assessed while he or she is receiving palliative care. Hospice care is a form of palliative care that is given to a person when cancer therapies are no longer controlling the disease. It focuses on caring, not curing. When a person has a terminal diagnosis (usually defined as having a life expectancy of 6 months or less) and is approaching the end of life, he or she might be eligible to receive hospice care.

6. Where do cancer patients receive palliative care?

Cancer centers and hospitals often have palliative care specialists on staff. They may also have a palliative care team that monitors and attends to patient and family needs. Cancer centers may also have programs or clinics that address specific palliative care issues, such as lymphedema, pain management, sexual functioning, or psychosocial issues.

A patient may also receive palliative care at home, either under a physician's care or through hospice, or at a facility that offers long-term care.

7. How does a person find a place that offers palliative care?

Patients should ask their doctor for the names of palliative care and symptom management specialists in the community. A local hospice may be able to offer referrals as well. Area hospitals or medical centers can also provide information.

8. What issues are addressed in palliative care?

Palliative care can address a broad range of issues, integrating an individual's specific needs into care. The physical and emotional effects of cancer and its treatment may be very different from person to person. For example, differences in age, cultural background, or support systems may result in very different palliative care needs.

Comprehensive palliative care will take the following issues into account for each patient:

- **Physical.** Common physical symptoms include pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath, and insomnia. Many of these can be relieved with medicines or by using other methods, such as nutrition therapy, physical therapy, or deep breathing techniques. Also, chemotherapy, radiation therapy, or surgery may be used to shrink tumours that are causing pain and other problems.
- **Emotional and coping.** Palliative care specialists can provide resources to help patients and families deal with the emotions that come with a cancer diagnosis and cancer treatment. Depression, anxiety, and fear are only a few of the concerns that can be addressed through palliative care. Experts may provide counselling, recommend support groups, hold family meetings, or make referrals to mental health professionals.

- **Practical.** Cancer patients may have financial and legal worries, insurance questions, employment concerns, and concerns about completing advance directives. For many patients and families, the technical language and specific details of laws and forms are hard to understand. To ease the burden, the palliative care team may assist in coordinating the appropriate services. For example, the team may direct patients and families to resources that can help with financial counselling, understanding medical forms or legal advice, or identifying local and national resources, such as transportation or housing agencies.
- **Spiritual.** With a cancer diagnosis, patients and families often look more deeply for meaning in their lives. Some find the disease brings them more faith, whereas others question their faith as they struggle to understand why cancer happened to them. An expert in palliative care can help people explore their beliefs and values so that they can find a sense of peace or reach a point of acceptance that is appropriate for their situation.

9. Can a family member receive palliative care?

Yes. Family members are an important part of cancer care, and, like the patient, they have a number of changing needs. It's common for family members to become overwhelmed by the extra responsibilities placed upon them. Many find it difficult to care for a relative who is ill while trying to handle other obligations, such as work and caring for other family members. Other issues can add to the stress, including uncertainty about how to help their loved one with medical situations, inadequate social support, and emotions such as worry and fear. These challenges can compromise their own health. Palliative care can help families and friends cope with these issues and give them the support they need.

10. How is palliative care given at the end of life?

Making the transition from curative treatment to end-of-life care is a key part of palliative care. A palliative care team can help patients and their loved ones prepare for physical changes that may occur near the end of life and address appropriate symptom management for this stage of care. The team can also 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 withdraw cancer therapy, grief counselling, and transition to hospice.

11. How do people talk about palliative care or decide what they need?

Patients and their loved ones should ask their doctor about palliative care. In addition to discussing their needs for symptom relief and emotional support, patients and their families should consider the amount of communication they need. What people want to know about their diagnosis and care varies with each person. It's important for patients to tell their doctor about what they want to know, how much information they want, and when they want to receive it.

12. Who pays for palliative care?

Palliative care services are usually covered by health insurance and private donations. If individuals are unsure about these costs, they should check with a social worker or their hospital's financial counsellor.

13. Is there any research that shows palliative care is beneficial?

Yes. Research shows that palliative care and its many components are beneficial to patient and family health and well-being. A number of studies in recent years have shown that patients who have their symptoms controlled and are able to communicate their emotional needs have a better experience with their medical care. Their quality of life and physical symptoms improve.

In addition, the Institute of Medicine 2007 report *Cancer Care for the Whole Patient* cites many studies that show patients are less able to adhere to their treatment and manage their illness and health when physical and emotional problems are present. To view this report, go to <http://www.ncbi.nlm.nih.gov/books/NBK4015/14>.

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