



Canadian Cancer Society
Société canadienne du cancer

Childhood Cancer

A guide for families



Let's Make Cancer History

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Introduction

Having a child with cancer is one of the biggest challenges a parent will ever have to face. You may be feeling:

- sad, guilty, angry or uncertain
- overwhelmed by emotions, information, responsibilities and scheduling
- physically and emotionally tired
- strapped for time
- anxious about how you will manage
- scared for the future

Some parents simply feel numb, at least for a little while:

“*Your son has cancer.*” When they said those words, a really funny sensation came over my body. I felt something drain out from the top of my head through my feet. Everything became a pinpoint focus on the doctor speaking. I knew I needed to focus in to listen, but it was a bit like listening to the adults on the Peanuts cartoon: wah wah wah.

All of these feelings are common and normal.

How to use this guide

This booklet was written for parents and caregivers of children with cancer (babies to teens). It describes basic medical concerns and issues that may be important to family life during your experience with cancer. You may find it useful to share it with friends and relatives who want to learn more about what you and your family are going through.

Because each person has a unique response to cancer, and every family's situation is different, some topics may have more meaning for you, or seem more useful than others.

We talked to parents of children with cancer to help make sure this guide would meet as many of your needs as possible. *Childhood cancer: A guide for families* was written to help you learn about:

- what cancer is and the different types of childhood cancer
- common medical procedures, cancer treatments and side effects
- how to work with hospitals and your child's healthcare team
- how to talk to your child about cancer
- how you and your family can cope with the changes and challenges to your lives that come with the cancer diagnosis
- what the future may hold
- where you can get more information

Parents also told us that they liked talking to other parents who have "been there". For this reason, we've included their words in quotes, and we've taken their advice on helpful tips and suggestions.

Read at your own pace

Parents were very clear that they needed to take their cancer journey one step at a time: they wanted to read only what they were ready to read, and what they needed to know at the time. You may want to read some of the sections right away, and come back to others later. Every chapter starts with a summary. Some chapters include suggestions on where to go for more information, when you're ready.



Understanding Childhood Cancer



Photographed by Hugh Wesley ©, PhotoSensitive

This chapter gives some basic information about how cancer develops and describes the more common types of childhood cancer. Topics include:

- what is cancer?
- a positive outlook for childhood cancer
- causes of childhood cancer
- types of childhood cancer

What is cancer?

Cancer is a disease that starts in our cells, which are the building blocks of every part of the body. 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 in some cells get mixed up, causing them to behave abnormally. These cells grow and divide uncontrollably and continue to form new abnormal cells. Although there are many kinds of cancer, all begin because of abnormal cells that grow out of control.

Groups of abnormal cells in the body's bones, organs, or tissues can form solid lumps, often called *tumours*. 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 the nearby tissues and spread to other parts of the body. It is important to find and treat malignant tumours as early as possible.

Most people think of cancer as a solid tumour. Abnormal cells in the immune system or the blood, however, do not form tumours. Instead, these cancer cells circulate in the lymph system, blood or bone marrow.

In general, cancer can be divided into three groups:

- *Solid tumours* are cancers of the bone, organs or other tissues in the body.
- *Lymphomas* are cancers of the lymph system.
- *Leukemias* are cancers of the blood and bone marrow.

Cancerous cells that spread to other parts of the body from where they first started are called *metastases*. If cancer spreads from where it started (the *primary* cancer), it still has the same kind of abnormal cells and keeps the same name as the primary cancer. For example, Wilms' tumour is a childhood cancer that starts in the kidney. If it spreads to the liver, it is called *Wilms' tumour with liver metastases*.

A positive outlook for childhood cancer

It's probably hard to think there is anything positive about your child's situation. But it's important to understand that cancer in children isn't the same as cancer in adults. The types of cancer, and how they develop and spread, are different in children. Childhood cancers are also treated - and respond to treatment - differently than adult cancers. While every case is different, the general outlook for childhood cancers is good.

Childhood cancer usually responds well to treatment. This means that more children than ever before survive childhood cancer.

Causes of childhood cancer

It's normal to wonder about what caused your child's cancer. Most parents do. Some parents worry that something they did, or something they exposed their child to, caused the cancer – that the cancer is somehow their fault.

In fact, we don't know the cause of most childhood cancers. While researchers are looking into this area, it's hard for them to uncover reliable answers because the disease is so complex and because the number of cases of childhood cancer is small.

A few things are known about childhood cancer:

- A few types of childhood cancer are hereditary (the gene for that cancer is passed from parent to child).
- Some genetic conditions or syndromes increase the risk of developing cancer.
- It's not contagious. Cancer isn't like the flu or a cold – your child didn't “catch” it from another person and can't pass it on to someone else.

Types of childhood cancer

Many types of childhood cancer are described below in alphabetical order.

When you want to know more

If you want more information about the type of cancer your child has, we can help.

- Call an information specialist toll-free at 1 888 939-3333
Monday to Friday 9 a.m. to 6 p.m.
- E-mail us at info@cancer.ca.

Brain and spinal cord tumours

Also called *central nervous system (CNS) tumours*

This type of solid tumour starts in the central nervous system (CNS), which is made up of the brain and the spinal cord. Together, these organs control key bodily functions such as breathing, heart rate, movement, thinking and learning. Hormones produced in the brain stimulate and control many other organs in the body. There are several different types of brain tumours. The tumour types are grouped by where they develop in the brain and the type of affected cell. For example, a glioma begins in the glial cells of the brain.

The terms *benign* and *malignant* are not as useful when it comes to brain tumours. Any type of tumour in the brain can be harmful because of the pressure it can cause. The brain is encased in the skull and the spinal cord is protected by the vertebrae. These bony coverings don't allow room for even a small tumour to grow within them. Pressure on the brain can cause seizures and problems with balance, depending on the size and location of the tumour.

Ewing's sarcoma

Ewing's sarcoma is a type of bone cancer that can start anywhere in the body, but it most often affects the bones in the pelvis, leg, upper arm and ribs.

This bone cancer is a type of sarcoma. Sarcomas are solid tumours that start in the supporting structures of the body, such as bone, muscle or cartilage.

Germ cell tumours

Germ cell tumours are solid tumours that start from cells that usually produce eggs or sperm. The term *germ cell* refers to the life-giving properties of the cells, as in *germinate*. Germ cells don't come from germs or bacteria. Most germ cell tumours start in the ovaries or testicles. They can sometimes start in other parts of the body, such as the area at the bottom of the spine, the brain, chest and abdomen.

Germ cell tumours are not always cancerous, but can still cause problems by pressing on nearby tissue and body structures.

Leukemia

Leukemia is a cancer of the blood that starts in blood-forming tissue such as the bone marrow. It causes large numbers of abnormal blood cells to be produced. These abnormal cells sometimes enter the blood. There are different types of leukemia, depending on what type of blood cell is affected and whether the cancer tends to grow quickly (*acute*) or grow slowly (*chronic*).

The most common type of leukemia in children is *acute lymphocytic leukemia (ALL)*, which is sometimes called *acute lymphoblastic leukemia*. It is also known as *childhood leukemia*.

Acute lymphocytic leukemia is a fast-growing type of leukemia in which too many abnormal white blood cells (called *lymphoblasts*) are found in the bone marrow and sometimes in the blood as well.

As the numbers of lymphoblasts increase in the bone marrow, there is less room for other healthy blood cells to be produced.

Other types of leukemia, such as *acute myelogenous leukemia (AML)* and *chronic myelogenous leukemia (CML)*, which involve different cells, are more common in adults but can also occur in children.

Liver cancer

Liver cancer starts in the cells of the liver. The liver normally removes waste products from the blood, releases substances that help blood to clot, and helps digestion. It has an amazing ability to repair itself and can function normally even if only a small part of it is working.

Hepatoblastoma and *hepatocellular carcinoma (HCC)* are the two main types of liver cancer in children. Hepatoblastoma occurs mainly in younger children, hepatocellular carcinoma in older children.

Lymphoma

Hodgkin lymphoma and *non-Hodgkin lymphoma* start in the lymph system, which is part of the immune system. The immune system is the body's natural defence against infection and disease.

The lymph system includes the bone marrow, thymus, spleen, tonsils and lymph nodes throughout the body.

Because lymph tissue is in many parts of the body, lymphoma can start almost anywhere.

In children, Hodgkin lymphoma tends to affect the lymph nodes that are close to the body's surface, such as those in the neck and armpit, and sometimes in the groin area.

There are many types of non-Hodgkin lymphoma. The most common types in children and adolescents are lymphoblastic lymphoma, Burkitt's lymphoma and Burkitt's-like lymphoma. Other types of non-Hodgkin lymphoma that may occur are anaplastic large cell lymphoma and diffuse large B-cell lymphoma.

Neuroblastoma

Neuroblastoma begins in *neuroblasts*, which are immature cells in the sympathetic nervous system. The sympathetic nervous system is responsible for actions such as blushing, increasing heart rate or your pupils dilating. These are known as *involuntary actions*.

This solid tumour can occur anywhere in the body, but it usually starts in the abdomen, often in one of the two adrenal glands, which are just above the kidneys. Other common sites are the chest, neck or pelvis.

Osteosarcoma

Also called *osteogenic sarcoma*

Osteosarcoma is a solid tumour that starts in a bone. It can develop in any of the bones of the skeleton but often starts at the ends of the bones, particularly in the arms or legs. It most often affects the bones around the knee and in the upper end of the arm.

Osteosarcoma is a type of sarcoma. Sarcomas are solid tumours that develop in the supporting structures of the body, such as bone, muscle or cartilage.

Retinoblastoma

Retinoblastoma is a cancer of the eye. The tumour occurs in the retina, a thin layer of nerve tissue at the back of the eye that allows a person to see.

There are two forms of retinoblastoma. One form is inherited, which means it runs in families. This type of retinoblastoma often affects both eyes. The other type is non-inherited, which often affects only one eye.

Rhabdomyosarcoma

Also called *RMS* or *rhabdo*

Rhabdomyosarcoma (RMS) is a solid tumour that starts in muscle tissue, in cells called *rhabdomyoblasts*. It can grow in any part of the body. It is found most often in the head and neck, genital and urinary organs, arms, legs and trunk.

RMS is a type of soft tissue sarcoma. Soft tissue sarcomas are solid tumours that can develop in muscle, fat, blood vessels or in any of the other tissues that support, surround and protect the organs of the body.

Wilms' tumour

Also called *nephroblastoma*

Wilms' tumour is a solid tumour that starts in the kidney. The kidneys are a pair of organs located inside the body near the middle of the back. They filter waste out of the blood and produce urine. Wilms' tumour is usually found in one kidney (*unilateral*), but sometimes in both (*bilateral*).



When Your Child is Diagnosed



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When a child is diagnosed with cancer, families can feel overwhelmed. Hospitals, doctors, tests and procedures – there’s so much to take in. Fortunately, families don’t have to go through it alone. When your child is first diagnosed with cancer, you may need more information about:

- who’s who on the healthcare team
 - common medical tests and procedures
 - staging and grading
 - questions to ask about medical tests
-

Who’s who on the healthcare team

Many professionals come together and help your family through treatment and beyond. The healthcare team will help make sure that your child gets the best treatment available with as few ill effects as possible. They will help you and your child cope with both the physical and emotional effects of cancer, and help you find your way through the often complex healthcare system. As a parent, you are a vital part of the team that will take care of your child.

“ *All the members of the team sort of swarmed our hospital room: the physiotherapist, the radiologist, the psychologist, the social worker. I had a little book with me and a roll of tape and I took their business cards and taped them into the book. As you get to know them intimately over the weeks and months, you realize you do need them. They’re showing up to say, “We’re here for you.”* ”

The team working with your child may include many different healthcare professionals.

A **chaplain** is trained to offer spiritual care, support and prayer according to each family's individual spiritual and religious needs.

A **child life specialist** is trained in child development and how children react to illness and being in the hospital. Child life specialists use “play” to help children cope with medical procedures and cancer treatment. They help parents understand their children's behaviour and can offer advice to help parents support their children.

“ *I particularly liked the child life specialist. She used dolls with NG tubes and ports to explain and help us prepare for surgery and tests. My son could give the doll its medicine and understand what was going to happen to him.* ”

A **dietitian** helps with your child's nutritional needs during treatment. If your child is not able to eat for a while, a dietitian can help you understand and can suggest other ways of giving all the nutrients that your child needs, such as a feeding tube. Dietitians can also provide teaching and support about eating and drinking when your child goes home.

Your **family doctor** or **general practitioner** (GP) provides general, primary healthcare to your family.

A **hematologist** is a doctor who specializes in blood disorders, including leukemias and lymphomas. Hematologists examine samples of blood in the laboratory and also look after patients in the hospital.

A **nurse** provides daily nursing care for children in the hospital or clinic. Nurses often have the most contact with your child and will answer questions, give medicine and provide emotional support. **Oncology nurses** and **oncology nurse practitioners** have completed special training in caring for people with cancer.

“ *The key person on our team was the oncology nurse. I talked to her if I had any questions at all. She was the one who gave us the test results. She was the one who translated the oncologist’s “medical speak” for us.*

A **pathologist** analyzes samples of tissue (such as tissue taken at biopsy) under the microscope, to diagnose illnesses or see how cancer is being affected by the treatment.

A **pediatric oncologist** is a doctor who specializes in planning and giving cancer treatment for children.

A **pharmacist** prepares the medicine and nutritional support that your child will need.

A **physiotherapist** or **occupational therapist** works with children to restore or maintain physical fitness. They can help when children have a hard time moving around or carrying out daily activities.

A **psychiatrist** or **psychologist** is a mental health specialist. They can help you and your child understand, manage and cope with feelings, emotions, thoughts and behaviour.

“ *My daughter thought the psychologist was just great. He used a lot of humour to get through to her. He focused on her strengths. She had a particular fear of the heparin needle, and he worked with her to help her get over that fear.*

“ *My husband got depressed over the course of our son’s treatment. He went to a counsellor to talk about his feelings and also got antidepressants, and that helped a lot. It was really important for him to accept that he needed the help.*

The **radiation therapy team** works together to provide radiation therapy to your child:

- A *radiation oncologist* is a doctor who specializes in treating cancer with radiation. This member of the team develops the radiation treatment plan.
- A *radiation therapy nurse* provides information and support relating to treatment and, with other members of the team, helps you manage your child's side effects.
- A *radiation therapist* helps plan and deliver treatment. This member of the team, who you will likely see every day during treatment, also supports you in managing your child's side effects.

A **social worker** helps you and your child cope with illness and being in the hospital. Social workers can provide or refer you to counselling, support groups, financial assistance and other resources.

“ *Our social worker helped arrange our parking pass at the hospital and helped us get a free wig for our daughter.* ”

A **surgical oncologist** performs operations relating to cancer. For example, this doctor may take a biopsy, remove the tumour or put in a central line.

Teachers or **school liaisons** work in the hospital and the community to help your child keep up with school work during hospital stays. They can work with your child's school and regular teacher to plan an education program for your child.

Volunteers are trained as unpaid helpers with non-medical activities for your child. A volunteer might be able to play a game or read a book to your child, get you a cup of coffee or give you directions. Many volunteers in cancer hospitals or clinics have had a personal experience with cancer.



It's really important to understand each person's role on the team. When I had questions about my daughter's drugs, at first I asked the doctors, but in fact the pharmacists were the best ones to ask. Specialists are very focused on their specialties, so an oncologist isn't necessarily thinking about nutrition or drugs. If the doctor redirects you to the pharmacist, follow up. If you have questions about feeding or nutrition, ask your dietitian. If you don't see her at the clinic, page her.

Common medical tests and procedures

Many medical tests and procedures are needed to diagnose cancer in a child. Children may also have some of these tests repeated over the course of treatment. These tests are done to:

- make sure that the diagnosis is correct and accurate
- find out exactly where the cancer is in the body, the stage of the cancer and whether it has spread (*metastasized*) to other parts of the body
- decide on the right course of treatment
- get a general measure of your child's health, including how the organs are working, which may play a role in the kind of treatment that is given
- find out how well the treatment is working

It can take some time to get through the tests. Waiting for the results is very hard. But taking time to have the tests is important. The results will tell the healthcare team a lot more about your child's condition. This will help them plan the best possible treatment for your child.

Pain during tests

Unfortunately, some tests and procedures can be uncomfortable or painful for your child. For more information on managing pain during tests, see *Pain*, beginning at page 84.

Depending on the type of cancer, your child may have some of the following tests.

Angiogram

An angiogram is a type of x-ray that is done to produce a picture of blood vessels. A special dye is injected into an artery so that the blood vessels can be seen. An angiogram can be used to look at almost any blood vessel in the body.

An angiogram is not usually used to diagnose cancer, but it can help in planning treatment. It may be used to look at the blood supply of a tumour in the brain, spinal cord or kidney.

Biopsy

In a biopsy, a small piece of tumour or tissue is removed and examined to see if it is cancerous, and what type of cancer it is. There are different ways to do a biopsy:

- In a *needle biopsy*, the surgeon takes the tissue sample by passing a needle through the skin into the abnormal tissue or lump.
- In an *open biopsy*, the surgeon takes the tissue sample by first opening the skin and exposing the tissue or organ. Sometimes the surgeon may be able to remove the whole tumour rather than just take a biopsy.

Biopsies can be painful. To help manage pain, your child may have a local or general anesthetic.

Bone marrow aspiration and biopsy

Bone marrow is the soft, spongy tissue inside bone where blood cells are made. The bone marrow can be tested by bone marrow aspiration, biopsy or both.

A bone marrow aspiration uses a needle to take a small sample of liquid marrow for testing. Usually an aspiration of bone marrow fluid is taken from the back of the hip bone. Babies and young children may have the sample taken from the front of the lower leg bone, just below the knee.

A bone marrow biopsy uses a needle to take a small piece of solid marrow for testing. A bone marrow biopsy is only taken from the hip bone.

Your child may be given a general anesthetic for these tests. For an older child, a local anesthetic and sedation may be used instead. If awake during the tests, your child may feel some pain but it will only last a few seconds. Your child will probably be in the treatment room for about 30 minutes. You may be able to be in the treatment room as well.

Blood tests

Blood tests are performed on blood samples. Usually, blood samples are taken by inserting a needle into a vein, or by pricking the tip of a finger and squeezing out a few drops of blood. There are many different types of blood tests.

The blood has three main types of cells – red blood cells, white blood cells and platelets. A *complete blood count (CBC)* is a blood test that measures the number and quality of these blood cells. A CBC can:

- provide information about your child's general health
- show how well the bone marrow and spleen are working
- check for anemia and infection
- be a reference point to check future CBCs against
- keep track of the effects of treatment

Blood chemistry tests measure the levels of certain chemicals, such as sodium, glucose and creatinine. They give information about how well certain organs, such as the liver and kidneys, are working.

A *tumour marker test* looks for a substance that may increase in the blood of a child with cancer. For example, liver cancer cells make a protein called alpha-fetoprotein, or AFP. High levels of AFP may be a sign of cancer. Tumour marker tests can be used to help diagnose cancer and to find out how well the child is responding to treatment.

Creatinine clearance

This test measures how well the kidneys are working by testing how fast they remove a protein called *creatinine* from the blood. To do the test, urine is collected in a container for 24 hours. Creatinine is also measured in the blood.

CT scan

A CT (*computed tomography*) scan is a special x-ray that uses a computer to make a 3-dimensional picture of the organs, tissues, bones and blood vessels inside the body. This scan may be used to detect a tumour or find out its size or location. A CT scan may also be used to:

- find out how far the cancer has spread
- guide the surgeon during a biopsy
- help plan treatment
- find out how well treatment is working

Your child will lie on a narrow table and will be held safely in place with tape or Velcro bands. The table slides into the CT scanner, which looks like a tunnel. The camera moves around the body, taking pictures. A CT scan doesn't hurt, but your child may find it very hard or uncomfortable to lie still for so long.

The test, including preparation time, takes up to one hour. If your child needs to be sedated for the test, it may take longer (2 to 3 hours).

Echocardiogram

An echocardiogram (an *echo*) tests the strength and function of the heart. The test uses sound waves to create a picture of the heart. A clear jelly is placed on the chest. Then the person doing the test will apply a small round handle on the chest, to send sound waves to the heart and create a picture of it.

Having an echo doesn't hurt.

Lumbar puncture

A lumbar puncture (also known as a *spinal tap*) is performed to see if there are cancer cells or an infection in the fluid around the brain and spinal cord. A thin needle is inserted into the fluid between two spinal bones in the lower part of the spine, and a few drops of fluid are removed.

Your child may be given a general anesthetic, but sometimes a local anesthetic and sedation may be used for an older child. A baby or young child will be placed on their side, curled up with their knees under their chin. An older child or teen may sit leaning forward at the waist on a table or bed, with their head resting on a pillow and their back to the doctor.

This test may be painful, but the pain should only last a few seconds. The procedure should take 15 to 30 minutes. Your child should lie flat for at least an hour afterwards to avoid getting a headache.

MRI

MRI (*magnetic resonance imaging*) is a way to create a clear picture of most tissues and organs in the body. An MRI uses a powerful magnet with radio-frequency waves to produce signals that a computer forms into a picture. Different tissues react differently to the magnetic current and this produces various images. Some MRI scans need a special dye (*contrast medium*) to provide clearer images. An MRI can:

- help diagnose cancer
- find out how far cancer has spread
- help plan treatment

During an MRI, your child lies on a narrow table, and is held safely with Velcro bands. The table is moved into the magnet, which looks like a tunnel.

It doesn't hurt to have an MRI, but some children may need to be sedated in order to lie still enough for the whole test. The test

can take from 15 minutes to 2 hours. You may not be able to stay in the same room with your child during the MRI, but you can usually talk through an intercom.

Nuclear medicine imaging

Nuclear medicine imaging uses a *radiopharmaceutical* to look at tissues and organs. A radiopharmaceutical is a special dye that has a small amount of radiation. There are many types of nuclear medicine scans that look for cancer cells or infection in the body. Common types of scans used in cancer care include bone, gallium, GFR, MUGA, MIBG and PET scans.

Your child will lie on a special table. Keeping still is important for this test, so Velcro bands will hold your child safely in place. The dye is usually given by a needle into the hand or arm, but it may be given by mouth or breathed in. The dye goes to areas of the body where cancer cells are. A special camera and computer create pictures of this.

It doesn't hurt to have a nuclear medicine scan, but it can take up to a few hours to take the pictures. Your child may find it very hard or uncomfortable to lie still for so long. For babies and toddlers, sedation is often used.

Pulmonary function tests

Pulmonary function tests (PFT) look at how well the lungs are working. The tests measure how much air the lungs can hold, and how well your child can let air out of the lungs.

The machine that performs the PFT is in a small space with clear walls and a seat inside. Your child will be asked to wear a nose plug and blow into a cardboard mouthpiece on a long tube attached to a computer. (The procedure will be slightly different for babies and very young children.) The machine measures the amount of air breathed in and the force of the air breathed out. Your child will probably be asked to repeat the test a few times to get an accurate reading.

Ultrasound

An ultrasound is an imaging test that uses high-frequency sound waves to produce images of structures in the body. It works by bouncing sound waves off solid parts of the body. The image (called a *sonogram*) can be seen on a screen on the ultrasound machine. An ultrasound can help diagnose cancer and help plan cancer treatment.

Your child will lie down for the test and clear jelly will be placed on the part of the body that is being studied. A small hand-held device called a *transducer* is then placed on the jelly and moved around to get a clear picture of the tissue or organ that is being studied.

This test is usually quite quick (15 to 30 minutes) and does not hurt. Sometimes the pressure of the transducer on the body can be uncomfortable if it is placed on an area that is already sore.

X-rays

An x-ray is an imaging test that uses small doses of radiation. Unhealthy tissue often looks different from healthy tissue on an x-ray. Some x-rays use a special dye called a *contrast medium* to produce better images. An x-ray may help diagnose your child's cancer and monitor how treatment is going.

Your child will either lie on an x-ray table or sit in front of an x-ray machine. A lead apron may be placed over areas of the body that aren't being examined. The x-ray staff leave the room or go behind a shield to take the x-ray.

Having an x-ray doesn't hurt and usually only takes a few minutes.

Staging and grading

Once a definite diagnosis of cancer has been made, the cancer will be given a *stage* and a *grade*. This may mean having more tests. Knowing the stage and grade is part of planning the best treatment for your child.

The **stage** describes the extent of cancer in the body. The size of the tumour and whether it has spread beyond the place where it started to grow are important aspects of the stage. Most cancers are classed from stage 1 to 4, with stage 1 being cancer in an organ and stage 4 being cancer cells that have spread to other areas of the body, or *metastasized*.

Low grade or high grade is another way to describe some tumours. The **grade** describes how cancer cells look and act when they are viewed under a microscope. The pathologist looks for important things such as:

- how different the cancer cells look from normal cells
- how frequently the cancer cells are dividing
- whether the cancer cells tend to spread to other parts of the body

Sometimes a number from 1 to 4 is used to describe tumour grade. The higher the number, the higher the grade. Low-grade cancers tend to grow slowly and high-grade cancers tend to grow faster.

Different types of childhood cancer have different systems or ways of describing the stage and grade. Your doctor can tell you more about the systems used for the type of cancer your child has.

Questions to ask about medical tests

The following list of questions can help you decide what questions to ask members of your child's healthcare team. There may be a lot to remember, so you may find it helpful to write down the answer. You can also ask if it's okay to tape record the conversation, or bring a friend with you to listen or take notes.

“ *Ask, ask, ask. Ask as many questions as you need so that you can understand as much as possible. No question is stupid. In the beginning, you're kind of intimidated by the doctors and in shock, and your ability to take in information is limited. If you don't get it now, you might not get it later. If you're given an answer you don't understand, say so. Part of your duty as a parent is to communicate.*

- What tests do you need to do? Why?
- What will this test tell us?
- What risks, if any, are involved with the test?
- Who will perform the procedure?
- How is the test done? How long will it take?
- Where will the test be done? Will my child need to stay in the hospital?
- What will my child experience during the test? What will they see, hear, smell, taste or feel during the test?
- Will my child need to be sedated during the test?
- Do you have anything I can read about the test?

- How can I prepare my child for the test? Is there someone on staff, such as a child life specialist, who can help?
- Is the procedure painful? How will pain be managed?
- Can I (or someone else close to my child) be with my child during the test?
- What will happen if my child will not cooperate, or cannot be comforted or calmed?
- How will my child feel after the test? Are there any side effects?
- Are there special instructions to follow after the test?
- Can my child go back to school or out to play after the test?
- Who will give us the results? When will we receive them?
- Can someone show us the test results and explain them to us?
- Can we have a copy of the results?

Talking to Your Child about Cancer



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Many parents worry about how to talk to their children about cancer. In this chapter you'll learn about:

- being honest with your child
- practical tips on talking to your children
- kid-friendly explanations about cancer and treatments

Being honest with your child

A cancer diagnosis can be a scary thing to talk about with your child. For children, however, the world is scarier when they don't know what is happening or why. Although you may want to protect your child from the truth, there are good reasons to tell your child about their diagnosis, in a way that suits both your child's age and stage of development.

- Being honest helps your child build trust in you and the healthcare team. Children need to be able to trust the important people in their lives to tell them the truth.
- Your child will know what to expect, which can help with coping.
- Honest information helps correct any false ideas about cancer and cancer treatment. Children fill in gaps of information with their imagination. If children aren't given honest explanations, they may make up their own versions of what's wrong with them.
- Children may be more cooperative during treatments if they understand the importance of doing some things (for example, taking medicines, going to the hospital, and so on).
- Knowing and understanding their illness allows children to have a sense of control during times when they feel out of control.
- Children can sense when their parents are worried. Trying to hide the facts can make children even more anxious.

A child of any age may ask about death and dying. Dealing with the questions and fears that go along with this is very hard. It may come as a bit of a shock when and if your child asks questions on the topic. You may want to think about what to say in advance. If you're not sure of what to say, members of the healthcare team, such as the child life specialist or social worker, can help. Even though it's not easy to talk about it, your child should feel free to bring the subject up. These feelings need to be talked about and shared.

Your overall goal is to allow your child to express any feelings and ask questions about the cancer. A good way to discover what children already know, what information they want to know and what worries them is to ask if they have any questions about being sick.

Reassure your child

Children of all ages need to be reassured that they didn't cause the cancer. Younger children especially need reassurance that they are not in the hospital because they behaved badly or are being punished. Be prepared to repeat yourself often.

Practical tips on talking to your children

You may wonder, “How much should I tell my child?,” “How do I answer her questions?” or “What can I say to reassure him?”

Members of your child’s healthcare team, such as social workers and child life specialists, are a good source of help on these tough topics. These suggestions may also help:

- Follow your child’s lead. If they turn away to play or bring up another subject when you talk about their cancer, they may not be ready to talk.
- Be honest and open. Explain the illness and treatment to your child in a direct way. You can help make it less of a mystery.
- Give information out in small pieces that you can build upon as children need to know more. Children need enough information to know what will happen next, and to feel secure that their parents will keep them informed.
- Don’t be afraid to use the word “cancer”. Some parents don’t want to use the word “cancer” because they are afraid of scaring their child. But chances are your child will hear the word during conversations about treatment. This can be unsettling and confusing: If a mom tells her son only that he has leukemia, and later he hears his doctor use the word “cancer,” he may think, “I have leukemia and cancer, too?”
- Explain procedures before they are given. Explain what your child will see, hear, smell, taste or feel during the procedure, and talk about how to cope with the experience. This helps prevent your child from worrying about the procedures. It also helps your child trust medical staff and you.
- Let your child know about possible side effects of treatment. Otherwise, these effects can be frightening. For instance, tell your child that chemotherapy may cause hair to fall out.

- Listen as well as talk. Ask kids what questions they have.
- Admit that you don't have all the answers. If you aren't sure how to respond to a question, it's all right to say, "That's a good question. I don't know, so we'll ask the doctor." Then follow up.
- Consider using play to find out how your child is doing. Spending time playing together may give you insights into the thoughts, feelings and questions that they may not be able to express in conversation.
- Remember that emotions are okay. Many times children will feel angry, guilty, sad, lonely, scared and sometimes even happy. Let your child know that having feelings is okay. You can say, "I feel ..." or support your child and give words to their feelings: "I know you're angry ..."
- Be honest with your child about how you feel. Kids can sense when something is bothering you. Sharing your feelings sends the message that it's okay to feel upset or angry.

“ *Don't be afraid to show emotions. My son had quite a bad emotional reaction to one of the drugs he was given and said some awful things. He said to me, "You're happy that I had to go through this." When I asked him why he would say such a thing, he said, "Because you didn't cry. You've never cried." I told him, "If I had let myself cry, I never would have stopped." He said, "I wish that you would've cried because then I could have cried, too." Looking back, I would have let myself show more emotion.* ”

- Consider how kids might interpret your words. Children sometimes take terms and expressions literally, or misinterpret them. You can help prevent confusion by imagining how terms might sound to the child and then taking a minute to explain what the words really mean, or by using other words. (For example, sometimes undergoing general anesthesia is explained to kids as “being put to sleep” during their surgery. This wording may remind a child of a pet being “put to sleep”.)
- Limit your promises to things that are in your control. It can be tempting to say things like “The shot won’t hurt,” or “I promise everything will be okay.” It’s better to give a simple, honest answer and talk about how you will support your child. Instead of “The shot won’t hurt,” try something like, “I don’t know if it will hurt. Some kids say it feels like a little pinch, and some kids can hardly feel it. But I’ll be here to hold your hand the whole time, and you can let me know how it felt for you.” Rather than, “I promise everything will be okay,” try something like, “We are all going to do everything we can to help you get well, and we’ll be right here with you, going through it together.”
- Don’t worry if you have to repeat yourself. Children learn from doing, seeing and hearing things over and over.
- Ask for help. Most children’s hospitals have trained professionals, like social workers and child life specialists, who can help you find ways to explain cancer to your child.

Kid-friendly explanations about cancer and treatments

Use what you know of your child to determine how much they can understand and want to know about the cancer and their health. A child life specialist can also help you find ways to explain the diagnosis and treatment. Tools such as colouring books and teaching dolls can help your child understand. These explanations give you a starting point on many cancer-related topics.

What is cancer?

To help your child understand cancer, first talk about how cells in healthy bodies work. For example:

Your body is made up of things called cells. They're like the building blocks of our bodies. They're so small you can't see them, but every part of your body is made of cells – your hair, bones, blood, heart, skin, everything! In healthy bodies, cells work together to help us look the way we look and feel the way we feel.

After explaining how the healthy body works, talk about cancer. For example:

Sometimes some of the cells get sick. They don't know how to act and they can get out of control. They could make too many copies of themselves and crowd out healthy cells. Or they could grow the wrong way and not be able to do their jobs in your body. This causes problems for the healthy cells. Sick cells get out of control in different ways, and that leads to different kinds of cancer.

Try not to use the terms “bad cells” and “good cells” when talking about cancer. Instead, talk about “sick cells” and “healthy cells”. That way, your child is less likely to think they have “bad cells” because they are a “bad kid” or did something wrong.

Types of cancer

Then, talk to your child about the type of cancer:

Leukemia: *Our blood is made deep inside our bones, in the part of the bone called the bone marrow. Leukemia cells are sick blood cells that do not work properly and crowd out healthy blood cells. Then, your healthy blood cells can't do their jobs, and you can get sick.*

Lymphomas: *The body has a defence system, called the immune system. The immune system has fighter cells that live all over the body. The job of the fighter cells is to find cells that are sick or that don't belong in the body and get rid of them. When you have a type of lymphoma, the fighter cells that should be protecting the body don't work properly and can't do their job. They also crowd out the healthy cells in the immune system, which means they can't do their jobs either.*

Solid tumours: *A solid tumour happens when a sick cell in your [liver, kidney, brain, leg bone, the soft part or muscle of your arm] grows and multiplies out of control. After a while, there are so many sick cells that they make a lump, which is called a tumour. These sick cells crowd out the healthy cells and keep them from doing their job. They can also press on other parts of your body, which is why they hurt.*

What causes cancer?

When talking to your child about what causes cancer, you might want to explain that although a few types of cancer run in families, no one knows why most children get cancer.

It's important for your child to understand that people don't "catch" cancer and that cancer is not a punishment, or a person's "fault".

For example:

It's too bad, but nobody really knows why children get cancer. Cancer isn't like a cold – you didn't "catch" it from your friend and you can't "give" it to anyone else. Sometimes it just happens. It's nothing that you did wrong.

Types of treatment

Tell your child about the different types of treatment in the treatment plan. Explain that other children with different types of cancer may receive different types of treatment or different amounts of the same treatment.

Chemotherapy: *Chemotherapy, or “chemo”, is special medicine that helps get rid of sick cells.*

Radiation: *Radiation uses strong energy rays that you can't see or feel to get rid of cancer cells and stop them from growing and spreading. Machines send these invisible rays to the area of the body where the cancer is.*

Surgery: *Surgery is having an operation. A special doctor called a surgeon takes out all or part of the tumour. During surgery you are given medicine (anesthetic) that makes you go into a very special deep sleep until the surgery is done. You won't feel, hear or see anything during the operation, and you will wake up when it's over.*

Stem cell transplant: *Stem cells are kind of like seeds. All of our blood cells grow or develop from stem cells. Cancer or cancer treatment can hurt the stem cells. If this happens, you may need some new ones put in your body so that you can grow lots of new cells. Getting the new cells is called a stem cell transplant. A stem cell transplant has lots of steps and is very complicated. It's very easy to get sick after a stem cell transplant, so while you get better, you have to stay in a very clean room on your own so that you don't catch any colds or other illnesses.*

Side effects

Then, talk about side effects. You could say something like:

For cancer treatments to make you better, they need to be very strong and powerful. Because they're so strong, they sometimes hurt healthy cells while they are doing their job. When treatments hurt healthy cells, this can sometimes make you feel yucky or make funny things happen to your body. This is called having side effects.

There are different kinds of side effects, like feeling tired, having an upset tummy or throwing up. Not all children have side effects. If you do have them, we'll try different ways to make you feel better.

Your child's healthcare team can help

Your child life specialist can help you find ways to explain the diagnosis and treatment. They may use colouring books, teaching dolls, video games and other materials to help your child understand.

Treatment



Photograph courtesy of McMaster Children's Hospital

After your child is diagnosed, the healthcare team will put together a treatment plan that may include one or more types of treatment. This chapter talks about:

- your child's treatment plan
- giving consent to treatment
- clinical trials
- surgery
- chemotherapy
- radiation therapy
- biological therapy
- stem cell transplant
- questions to ask about treatment

Your child's treatment plan

Your child's treatment plan (which is also called a *protocol*) takes into account the type of cancer, its stage and grade. Your child's overall health and wishes are also an important part of the plan. Sometimes two children with the same cancer can be given very different treatments.

Many parents find it helpful to get a copy of the treatment plan to refer to as treatment goes on. The plan outlines:

- the exact type of treatment
- how often your child will receive treatment
- how long treatment will last

Treatment plans often change. Depending on how your child responds to treatment, the doctor may decide to change the treatment plan or choose another plan. While it can be comforting to know what's coming next, it's important to be prepared for changes to the protocol.

The treatment plan may seem complicated at first. But members of the healthcare team will explain each step.



When our son was diagnosed we were given a protocol. We planned way too far ahead on our calendar. We thought we could schedule everything. That's unrealistic. Things change. Not necessarily for the negative, but they just change. Our son's treatment was initially going to be for seven months, but it lasted over a year. For example, his red and white blood cells had to be at certain levels for chemotherapy and if they weren't at those levels, chemo was delayed. He also had a 7-hour surgery, and his chemo was delayed because he had to recover from it.

Children's cancer centres

Children's cancer centres are hospitals (or units in hospitals) that specialize in diagnosing and treating children and teenagers with cancer.

Children's cancer centres are staffed by a team of trained pediatric oncologists and other specialists. The pediatric oncologists at Canadian hospitals are part of the Children's Oncology Group (COG). This organization is responsible for finding the best ways to treat children with cancer in Canada, the United States and other countries. Through COG, oncologists receive information about new treatment plans and improvements to existing protocols as soon as they are known.

Giving consent to treatment

Before your child has any treatment, doctors will explain the goals of the treatment – including the benefits, risks and side effects – and will ask you to sign a form that gives permission (or *consent*) for treatment to go ahead. Depending on how old your child is and hospital policy, your child may also be asked to give consent or assent. *Assent* may apply to children who are not old enough to provide consent but are able to understand that they have

cancer and require treatment. Before you sign the form, you should be given full information about:

- the type and extent of the treatment recommended for your child
- the advantages and disadvantages of the treatment
- any other types of treatments that may be appropriate
- any significant risks or side effects of the treatment

If you don't understand what you've been told, say so right away so that it can be explained again. Many people need to hear explanations about cancer treatments a few times before they really understand them.

Clinical trials

After diagnosis, someone on your child's healthcare team will likely ask whether you would like to enroll your child in a research study called a *clinical trial*. A cancer treatment trial searches for better ways to treat cancer and help improve cancer care.

Clinical trials are the only reliable way to find out if new drugs and new methods of surgery or radiation are better than the cancer treatments being used today. Studies may also look at new types of therapy or how to combine therapies or use an existing drug in a new way. All of today's recognized cancer treatments were tested and proven by clinical trials before they became available for general use.

Usually, in a clinical trial, children in one group receive the *standard treatment*, which is often the best result of the last clinical trial. Children in another group receive the new treatment. This new treatment is often very similar to the standard treatment, but with different doses or combinations of drugs.

Benefits and risks of clinical trials

Possible benefits

- Your child may receive treatment that is not otherwise available, which might be safer or more effective than current treatment options.
- Even if your child doesn't receive the new treatment being tested, you can be sure that your child will receive the best standard cancer treatment available.
- Your child may benefit from the extra follow-up care provided for participants.
- You take an active role in a decision that affects your child's life. This can be personally empowering and give you a sense of control.
- Your child has a chance to help others and to improve how cancer is treated.

Possible risks

- New treatments under study are not always better than, or as good as, the standard ones.
- Your child might have unexpected side effects that may be worse than those caused by standard treatments. Your trial team will carefully watch your child for reactions during the study.
- The new treatment may not work for your child, even if it helps others. This is true for all treatments, even the ones that are currently used as standard treatment.
- Being in a trial may take more time than standard treatment would or it may be inconvenient. Your child may need to have more tests or take extra medicines.

It's your choice

Whether your child participates in a clinical trial is a personal decision. If you decide not to enroll at all, or if you decide to remove your child from a trial, your child will continue to receive the best standard treatment available. Your choice will not affect how the healthcare team feels about you or your child.

For more information on clinical trials, contact the Canadian Cancer Society:

- Call an information specialist toll-free at 1 888 939-3333
Monday to Friday 9 a.m. to 6 p.m.
- E-mail us at info@cancer.ca.

Surgery

Children with solid tumours usually need some type of surgery as part of their treatment. Depending on the size and position of the tumour in the body, doctors may perform surgery to remove it. They may also remove tissue around the tumour and nearby lymph nodes.

Different kinds of surgery have different purposes in treating cancer:

- **Primary surgery** removes all or most of the tumour. In some cases, surgery is done after chemotherapy or radiation therapy has helped shrink the tumour.
- **Second-look surgery** is done after treatment with chemotherapy or radiation. The surgeon is able to see how well the treatments have worked in destroying the cancer cells and may be able to take out the remaining tumour.
- **Supportive care surgery** is done to help with some part of your child's care. For example:
 - > putting in a central line that can be used to give chemotherapy or take blood samples
 - > putting in a feeding tube to provide nutrition if your child can't get enough nutrition through eating

Dealing with fears about surgery

Your child might worry about surgery, its effects, having anesthetic, and whether it will be painful. These suggestions can help your child prepare for surgery:

- Answer your child's questions honestly. Your child may lose trust in you if what you say doesn't match what really happens. Your child needs to trust you.
- Learn as much as you can about the operation. This way, you can answer your child's questions correctly. Your doctors and other members of the healthcare team can give you the facts you need to prepare your child.
- Visit the operating and recovery rooms before the surgery. To help children get ready for surgery, many hospitals encourage them to visit the rooms where they will be during surgery and recovery. They can meet and talk with the people who will be there, and see some of the equipment. For instance, young children may be shown a surgical mask and given one to try on or to put on a toy or another person.
- Explain that your child will be given medicine (*anesthetic*) to go into a very special deep sleep, and not feel anything, until the surgery is done. Make sure your child understands that they will wake up after the surgery and you'll be there waiting.
- Talk to your child about their feelings and concerns about the surgery.

Side effects of surgery

Common side effects include pain, headaches, nausea and constipation. Your child's doctor may give you some idea of what to expect and what you need to watch for. These effects may be from the surgery, pain medicine or lack of exercise. Your child's doctor can give your child medicine, as needed, to help ease these side effects and other symptoms.

Chemotherapy

Chemotherapy is the use of chemicals or drugs to treat cancer. Often, a combination of chemotherapy drugs is used.

Chemotherapy drugs may or may not destroy cancer cells the first time they are given, and some cancer cells will survive and continue to grow. Chemotherapy is given according to a plan or schedule intended to destroy as many cancer cells as possible. Chemotherapy treatment is often repeated and is usually given at regular intervals called *cycles*. Each cycle of chemotherapy treatment is usually followed by a rest period (such as several days or weeks) when no treatment is given. This allows normal cells to recover.

The length, timing and number of cycles a child receives depend on the combination of drugs and the type of cancer being treated.

Chemotherapy drugs may be injected into a vein, a muscle, just under the skin, or into the spinal fluid or a body cavity. They can also be taken in pill or liquid form. Chemotherapy is often given through a *central line*.

Central lines

Also called *central venous catheter* or *central venous line*

Children being treated for cancer usually need to have lots of needles for many reasons (for example, to receive chemotherapy, for extra fluids, nutrition or blood tests). A special tube called a *central line* can be put into a vein so that the child will not need as many injections. Fewer injections means there will be less damage to veins.

There are three different types of central lines commonly used in children:

Tunnelled central line: A tunnelled central line is a thin, flexible, plastic tube that is inserted into a vein near the collarbone. The surgeon makes a small cut into a vein in the neck and feeds the tube down until the tip is in one of the large veins near the heart. The other end of the tube is then tunnelled under the skin and comes out on the front of the chest. A tunnelled central line is usually put in under a local or general anesthetic.

PICC line: A peripherally inserted central venous catheter (PICC) is a long, thin tube inserted into a vein in the crook of the arm. The line is put in under local or general anesthetic. Once in place, the PICC line is taped firmly to your child's arm to prevent it being pulled out of the vein.

Subcutaneous port: Some tubes do not come out through the skin. Instead, they end in a "port" under the skin, below the collarbone. To give chemotherapy or take blood, a small needle is pushed through the skin into the port. The skin over the port can be numbed with anesthetic cream before the port is used.

The healthcare team will let you know if your child should avoid certain activities, and how to take care of the line or port.

Side effects of chemotherapy

Chemotherapy attacks cancer cells and healthy cells throughout the body. The damage to healthy cells causes side effects such as hair loss, mouth sores, nausea and vomiting. This damage is usually temporary. Most side effects will disappear once the treatment is over.

A potentially serious, but rare, side effect of chemotherapy can be an allergic reaction to the drug. Your child will be closely watched for an allergic reaction, especially when the drug is first given.

Alert – Allergic reaction

Signs of a reaction include:

- developing sudden or severe itching
- breaking out in a rash or hives
- wheezing or having trouble breathing

If your child has any of these symptoms while being treated in the hospital, let a member of the healthcare team know right away. If you're at home, go to your nearest emergency room or call 911.

Talk to the oncologist about your child's chemotherapy drugs, so that you understand potential side effects and if they will occur.

Radiation therapy

Radiation therapy uses a certain type of energy (radiation) from x-rays, gamma rays, electrons and other sources to destroy cancer cells. Radiation in high doses destroys cells in the area being treated by damaging the DNA in their genes, making it impossible for them to grow and divide.

Doctors may use radiation therapy before surgery to shrink a tumour. After surgery, radiation therapy may be used to stop remaining cancer cells from growing.

Different types of radiation therapy

Different types of radiation therapy are used for different types of cancer. The information in this booklet focuses on external beam radiation therapy, which is often used for childhood cancer.

In **external beam radiation therapy**, radiation beams are directed at the cancer and surrounding tissue from a machine outside the body.

Your child's healthcare team will talk to you about what to expect and how to prepare if your child is going to have internal radiation therapy, such as:

Brachytherapy: a form of internal radiation therapy in which radioactive sources are implanted directly into the tumour or body cavity in which the tumour is growing. Surrounding tissues are spared the effects of the radiation.

Systemic radiation therapy: a form of internal radiation therapy in which radioactive substances are either swallowed or injected into a vein and travel throughout the entire body. They eventually gather at the tumour site and deliver radiation directly to the tumour.

Getting ready for external beam radiation therapy

Radiation therapy needs a lot of careful planning. The planning may take a few visits.

To make sure that radiation therapy is aimed precisely at the same place on the body every time treatment is given, your child will go through *simulation*. During simulation, the radiation therapist will place your child on a CT scanner or simulation machine in

the exact position that will be used during the actual treatment. They will measure your child's body and mark the skin to help direct the beams of radiation to the right locations.

A member of the team may make a clear plastic mould that will help your child keep still and in the right position each time the treatment is given.

What happens during radiation therapy?

Radiation therapy itself isn't painful. Your child won't see, feel or taste the radiation. It's much like having a regular x-ray taken, except that your child needs to hold still for longer. Because it's hard for some young children to be still, the doctor may give them medicine to help them relax or sleep.

The parts of your child's body that are not being treated will be covered by special shields made of lead to protect them from the radiation.

The treatment may take only a few minutes, but your child will probably spend 15 to 30 minutes in the treatment room. It takes time to get in place on the treatment table and check the machine settings.

Once your child is in place, the radiation therapist will leave the room to turn on the machine. The machines used for treatment are quite large. They can also make strange noises as they work and move about. The machine can be stopped at any time if your child feels sick or uncomfortable.

Your child will have to be alone in the room during the treatment but will be able to talk to the radiation therapist, who will be watching and listening from the next room. You can usually be with the radiation therapist, so that you can see and talk to your child. Radiation therapists constantly check to make sure everything is working as it should. They might come back into the treatment room to change the machine's position from time to time.

Your child isn't radioactive during or after the treatment, so you don't need to worry about being close to your child once treatment is finished.

Dealing with fears about radiation therapy

- Some children find the radiation machines scary at first. Try to have a tour of the area before the first treatment, so you can see what the machines look like. Being familiar with the machines and the procedures can make things less scary.
- Many children are uncomfortable with the idea of being left alone in the treatment room. Your child may feel better knowing that you will be close by and watching. During treatment, you can talk, tell stories or play music for your child over the communication system.

Radiation therapy side effects

Radiation therapy harms both cancer cells and healthy cells, but most healthy cells can repair themselves after treatment is over. With radiation therapy, the side effects often depend on the type of radiation therapy, the treatment dose and the part of the body being treated. The most common side effects of radiation therapy include fatigue, red or blistered skin and other skin changes, hair loss, low blood cell counts, nausea and vomiting, dehydration and mouth sores.

Ask your doctor about possible side effects and talk to your child's healthcare team about any side effects your child may have.

Biological therapy

Biological therapy uses natural or manufactured substances to strengthen the body's own immune system to help destroy cancer cells. The immune system is a complex system of cells and organs that work together to defend our bodies against infection and disease.

Biological therapy is also called *biological response modifier (BRM) therapy*, *immunotherapy* or *biotherapy*. Biological therapies are mainly given by injection.

Biological therapy is given to:

- interfere with cancer cell growth
- help healthy immune cells control the cancer
- lessen side effects by helping to repair normal cells damaged by other cancer treatments

Treating cancer with biological therapy is still very new. Many biological therapies are still being studied.

Side effects of biological therapy

Biological therapy can cause side effects such as flu-like symptoms, fatigue, skin changes, a rash or swelling at the injection site and mouth sores. The healthcare team may also alert you to other side effects which, while rare, can be serious.

Ask your doctor about possible side effects and talk to your child's healthcare team about any side effects your child may have.

Stem cell transplant

A stem cell transplant replaces your child's stem cells, which are the basic cells from which all blood cells develop. Stem cells are found in the bone marrow. A stem cell transplant is used to restore bone marrow when it has been damaged by disease or destroyed by high doses of chemotherapy or radiation therapy.

It is also called a *bone marrow transplant*.

Stem cells for your child can come from:

- umbilical cord blood (blood that is collected from the umbilical cord shortly after a baby is born and stored in a cord blood bank)
- bone marrow
- circulating blood (after being stimulated by drugs to release them from the bone marrow into the blood)

A stem cell transplant is a risky and complex procedure. For this reason, stem cell transplants are done in specialized transplant centres or hospitals by a team of highly trained healthcare professionals.

A stem cell transplant may be used to treat cancer when:

- The type of cancer has been shown to respond well to high-dose chemotherapy.
- There is a high risk of the cancer coming back.
- The cancer has come back after initial treatment.
- The cancer did not fully respond to the initial treatment.

Types of transplants

There are 3 basic types of stem cell transplant:

Allogeneic: The stem cells are taken from one person (the *donor*) and are given to the child with cancer (the *recipient*). The donor may be a relative or person who is not related to the recipient. The donor and recipient are matched through a process called *HLA typing*.

Autologous: The stem cells are taken from the child's own bone marrow or blood when the child is in remission (when the signs and symptoms of cancer have disappeared).

Syngeneic: The stem cells are taken from a donor who is the identical twin of the child with cancer.

How stem cell transplants are done

There are 3 stages in a stem cell transplant procedure: preparation, transplant and aftercare.

Stage 1: Preparation (pre-transplant)

Before the stem cell transplant, many medical tests and procedures are done to check that the child is a good candidate. Then, stem cells are collected (or *harvested*) from the bone marrow or blood of your child or a donor.

When stem cells are harvested from the bone marrow, a needle is inserted into the back of the hip bone, where a large amount of active marrow (a thick, red liquid) and stem cells are located. Doctors use a special needle with a syringe to remove the bone marrow. To get enough marrow, the needle is removed and a new one is re-inserted several times. A pressure bandage is put over the puncture site.

This procedure is usually done under a spinal or general anesthetic in an operating room. There may be some pain following this procedure (like having had a hard fall), which can be relieved by

pain medicine. Infection is not a common side effect. Blood loss and anemia are more common but are not usually severe.

If the bone marrow has been taken from the child with cancer, then the marrow may be treated to make sure that any remaining cancer cells are destroyed.

When stem cells are harvested from the blood, the person providing the stem cells is given a drug to help the bone marrow make more stem cells and release them into the blood. This is called *stem cell mobilization*. The drug may cause some side effects, such as bone and muscle aches, fatigue or flu-like symptoms, which disappear when the drug is stopped.

When there are enough stem cells in the blood, a special machine filters the blood to collect the stem cells and return the rest of the blood to the body. This is called *apheresis*. During apheresis, young children may need to be sedated or monitored in the intensive care unit (ICU) because a lot of movement can make it harder for the machine to remove stem cells.

When a sibling donates stem cells

Meeting with a social worker or child life specialist can help siblings cope with the medical procedures and with feelings about donating stem cells to a brother or sister.

A brother or sister who gives their marrow or stem cells to help a sibling often feels an enormous amount of pressure. Child donors are often told that they are helping to save their sibling's life. If the transplant doesn't go well, the donor may feel responsible and suffer guilt and depression.

If other siblings in the family were not chosen to be the donor, it's important to think about their feelings too. They need to understand that being able to donate stem cells is a random event, and not a measure of how important they are within the family.

Stage 2: Transplant (including conditioning therapy)

The child with cancer is prepared to receive the cells (*conditioning therapy*). The first part of conditioning therapy is to give high-dose chemotherapy, and sometimes radiation therapy, to:

- “condition” the bone marrow to accept donor stem cells (in an allogeneic or syngeneic transplant)
- remove any remaining cancer cells in the body
- destroy the bone marrow and make room for new stem cells

Then, in a process similar to a blood transfusion, the stem cells are given (*infused*) to the child over 1 to 2 hours through a central line. The day the stem cells are given is usually referred to as Day 0.

Once infused into the body, the stem cells naturally travel to the bone marrow, where they begin to grow and make new blood cells.

Stage 3: Aftercare

The days after transplant are called Day +1, Day +2 and so on. The new blood cells begin to appear and reproduce within about 2 to 4 weeks. This is called *engraftment*. The period between the conditioning therapy and engraftment is the most critical. Waiting for new marrow to begin working is likely to be a stressful time for you and your child as you watch for serious side effects and wait to see if the graft has taken (the transplant was a success). Your child will likely feel tired and unwell. At this stage, children are at high risk of developing serious infections because they have no white blood cells to fight infection.

The healthcare team will watch your child closely to prevent or treat any symptoms or side effects caused by the transplant as early as possible.

During this time, your child will be in protective isolation – a special, very clean room designed to reduce the risk of spreading infections. During isolation, you, your child and anyone who comes in contact with your child must follow strict rules about handwashing, and cleaning personal items. Visitors are limited. Your child will have daily baths with special antibacterial soap, and frequent mouth care each day.

To help your child cope with feeling bored and isolated, you might:

- decorate the room
- have a good supply of puzzles, games and books
- encourage phone calls, letters and pictures from friends and family
- bring in favourite toys, clothes or blankets (once they have been specially cleaned)
- be active whenever possible

After engraftment, your child may be under fewer restrictions and may be able to wear a mask to walk around the ward or go to a play area.

Your child will be carefully followed up for a period of time after leaving the hospital. Complete recovery can take a long time – from several months for an autologous transplant to two years for an allogeneic transplant.

Graft-versus-host disease

Children receiving transplants are watched very closely for side effects, which can be life-threatening. The most serious side effect is graft-versus-host disease (GVHD). In GVHD, healthy transplanted (*graft*) cells recognize the recipient's (*host*) cells as foreign and start to attack them.

GVHD is a risk almost always when the donor is someone other than the child with cancer or an identical twin. The better the match between donor and recipient, the greater the chance that the recipient's body will accept the donated stem cells, and the lower the risk for GVHD.

Symptoms of GVHD can affect the skin, gut (digestive tract, including the mouth), liver and other organs. If your child's healthcare team suspects GVHD, they may do a biopsy to confirm the diagnosis.

Drugs that suppress the immune system, including steroids, may be used to prevent and treat GVHD. Your child may need to take drugs for months or years after the transplant.

Questions to ask about treatment

The following list of questions can help you decide what to ask your child's doctor or healthcare professional. There may be a lot to remember, so you may find it helpful to write the answer down. You can also ask if it's okay to tape record the conversation, or bring a friend with you to listen or take notes.

- What are the treatment choices?
- Which treatment do you recommend and why?
- What are the chances that this treatment will be successful?
- Will my child have to stay in the hospital?
- What is the treatment schedule? How long will treatment last?
- What are the possible side effects or risks of this treatment?
- What can be done if side effects occur?
- How can I help prepare my child for this treatment?
- Do you have any suggestions on the best way to support my child through treatment?
- Will the treatment disrupt my child's school schedule? Will my child need tutoring?
- Is there a child life specialist on staff here to plan play therapy, school work and other activities?
- How will we know if the treatment is working?

Coping with Side Effects



Photographed by Dinah Ener ©, PhotoSensitive

When cancer treatment destroys cancer cells, it can also damage healthy cells. This damage to healthy cells causes side effects. Side effects, and how serious they are, vary from child to child. Your child's healthcare team will let you know what side effects need to be reported right away. This chapter:

- describes some of the common side effects of cancer treatment
 - suggests ways you can try to prevent or cope with side effects
-

Anemia

Chemotherapy can lower the number of red blood cells. Red blood cells carry oxygen to all parts of your body. When the red blood cell count is low, the body's tissues don't get enough oxygen to do their jobs properly. This is called *anemia*. Talk to your child's healthcare team if your child is tired, dizzy or short of breath. These are all symptoms of anemia.

If your child develops anemia, the healthcare team may decide to change the dose of chemotherapy in each treatment. They may recommend medicines to increase red blood cell counts or blood transfusions to build up red blood cells.

To help prevent and manage the effects of anemia:

- Make sure your child gets plenty of rest to help keep up energy levels.
- Limit activities to what are most important or necessary. If possible, let your child help decide what matters most. Do the most important things before your child runs out of energy.
- Do what you can to help your child move slowly. This will help with dizziness. For example, when getting out of bed, have your child sit on the side of the bed for a while before standing up. Your child's healthcare team may have other tips.
- Make sure that your child is getting enough iron. Your child's dietitian can help you choose foods that are high in iron.

Behavioural changes

Some drugs can cause feelings of anxiety, restlessness, dizziness, sleeplessness or headaches. Some children also find it hard to concentrate on anything. Understand that being moody or irritable may be normal for your child at this time.

“ *I experienced incredible temper tantrums with my son, who was 3 years old, and couldn't verbalize his rage and his anger against treatment. The drugs affect children's moods. He became irritable. A simple "no" provoked a tantrum. He was constantly tearing out his feeding tube – he was that angry. He couldn't control himself any more. Even he didn't seem to quite understand what was happening to him. I was terrified to see him in such a state. It's with the help of a child psychiatrist that I was able to tame his tantrums, which allowed me to be more tolerant and understanding.* ”

If your child has any of these side effects, talk to the healthcare team.

Bladder, kidney and urinary tract changes

Some chemotherapy drugs can affect the bladder or kidneys. Depending on the drugs, your child's urine may change colour. Some drugs can make urine smell like strong medicine.

These tips may help:

- Give your child plenty of fluids, especially on the day of treatment. The amount of fluids depends on your child's size, so discuss this with your child's doctor.
- Avoid caffeine (cola, coffee, tea).

Call your healthcare team – Signs of a bladder, kidney or urinary tract infection

- a burning feeling when urinating
- urine that is a reddish colour or blood in your child's urine
- the need to urinate often
- not being able to urinate at all
- the feeling of needing to urinate right away
- a fever or chills (especially chills that make your child shake)

Call the healthcare team if your child has or reports any of these signs.

Bleeding and bruising

Chemotherapy can affect the body's ability to make *platelets*, the blood cells that help the blood to clot. Without enough platelets, your child may bleed or bruise more easily than usual, even after a minor injury. If the platelet count becomes extremely low, your child may need a platelet transfusion.

Talk to the healthcare team or pharmacist before giving your child any over-the-counter medicines such as pain relievers, cold remedies, vitamins or herbal preparations. These can affect the platelets' ability to do their job.

Call your healthcare team – Signs of a low platelet count

- bruising easily or red spots under the skin
- unusual bleeding from the gums or nose
- unusual bleeding from the bladder or rectum (your team will explain how to watch for signs of blood in urine or stools)
- for teenage girls: vaginal bleeding that is different from their normal menstrual period

Call the healthcare team if your child has any of these signs of a low platelet count.

To help prevent and manage bleeding and bruising:

- Don't give your child ibuprofen (for example, Motrin or Advil) or any medicines containing Aspirin. They decrease the blood's ability to clot.
- Have your child avoid contact sports and other activities that might result in an injury.
- Use cotton swabs instead of a toothbrush to clean your child's teeth and do not floss.
- Have your child be very gentle when blowing their nose. Treat nosebleeds by applying soft pressure to the nose, just below the bridge. Pinch the area with your thumb and finger. Hold the pressure for 10 minutes. If it doesn't stop, call the doctor.
- Take steps to make sure your child doesn't become constipated. Constipation can lead to hemorrhoids, which can bleed.
- Don't take your child's temperature in the rectum. If you have to check your child's temperature, do it by mouth or ear.

Constipation

Pain medicines, some chemotherapy drugs, radiation to the stomach area or the location of a tumour can all cause constipation. A low-fibre diet, a lack of exercise and not drinking enough fluids are also possible causes.

These tips may help with constipation:

- Offer lots of high-fibre foods, including breads, cereals, pastas and rice made from whole grains; fruit, especially berries, dried fruit and citrus fruit; vegetables, especially broccoli, carrots, corn, leafy greens; lentils and beans.
- Add extra fruit and vegetables to your child's food. You can add fruit to smoothies, gelatin and desserts, or as a topping to yogurt or pancakes and waffles. Try adding extra vegetables to soup, pasta sauce, salads or sandwiches. It's okay to use the blender

or food processor to hide vegetables in foods like spaghetti sauce, chili, curry or shepherd's pie. Puréed fruit or shredded veggies can be added into muffin mixes and pancake batters too.

- Give lots of fluid, including water, milk, soup or juice. Prune juice is high in fibre and provides extra fluid.
- Encourage your child to exercise more, if able.

If your child is having trouble with bowel movements, the healthcare team may prescribe medicine or recommend a stool softener or laxative. Talk to your doctor and dietitian if constipation gets worse or lasts a long time.

Diarrhea

Your child may have loose or watery stools (bowel movements) as a side effect of cancer treatment. It's important to recognize and treat diarrhea early so that your child doesn't become dehydrated.

These tips may help with diarrhea:

- Limit insoluble fibre foods (also known as *roughage* foods), which are harder for your child to digest. Examples are whole grain breads and most raw vegetables and fruit, including berries, dried fruit and fruit with skins. Canned or well-cooked vegetables and fruit may be easier to digest.
- Add more soluble fibre to your child's diet. Soluble fibre is easier to digest. Offer oatmeal, potatoes, oat bran bread, applesauce, bananas and rice.
- Avoid foods that produce gas such as beans, lentils, broccoli, cauliflower, cabbage, carbonated beverages and chewing gum.
- Limit high-fat foods like fried meats, French fries, greasy snack foods, higher-fat milk products, rich desserts and added fats like butter or margarine.
- Limit foods that contain lactose, including milk, milkshakes, pudding, cheese or ice cream. You can, however, offer yogurt, since it contains "good" bacteria that help with digestion.

- Avoid large amounts of sweetened beverages like fruit drinks, juice, punch, pop or iced tea.
- Give your child foods high in salt and potassium if the diarrhea is severe and lasts a long time. Store-bought broths and soup are a good source of sodium and provide extra fluids. Sports drinks may also help, but check with your child's dietitian. High-potassium foods like potatoes and bananas are also important because they contain soluble fibre. Your doctor can also prescribe oral potassium supplements.
- Give drinks that replace electrolytes that are made for children.
- Have your child soak in a tub of warm water.
- Put a warm hot-water bottle wrapped in a towel on your child's abdomen to relieve pain and discomfort. Don't use a heating pad as the skin may be very sensitive to heat, especially if your child is having chemotherapy or radiation therapy.
- Resume your child's normal diet gradually once the diarrhea goes away.

Call your healthcare team – Diarrhea and dehydration

Diarrhea can lead to dehydration (loss of fluids in the body). Some common signs of dehydration include:

- dry skin or mouth
- no tears when crying
- infrequent urination or small amounts of dark-coloured urine

Call the healthcare team if you think your child might be dehydrated.

Dry mouth

Some cancer treatments affect the salivary glands, leaving your child with a dry mouth.

These tips may help with dry mouth:

- Offer moist foods and liquids with foods to help your child swallow more easily.
- Have an older child suck on a hard candy or chew gum to increase saliva. Sucking on ice chips can also help moisten the mouth.
Alert: choking hazard for young children
- Offer frozen grapes, strawberries or blueberries, or popsicles.
- Offer your child sweet or sour foods. These foods help stimulate saliva production.
- Add butter, margarine, sauces, mayonnaise, gravy or salad dressing to vegetables, pasta, meat or baked goods. This will help moisten foods and make them easier to swallow.

Mouth care during treatment

A dry mouth can lead to tooth decay, so it's important to take extra care of your child's teeth and mouth.

- Children receiving radiation should rinse their mouths often during the day. One suggested mouth rinse: mix 2 mL (½ tsp) of salt and 2 mL (½ tsp) baking soda in one cup of water.
- Your doctor or dentist may recommend using a fluoride mouth rinse or gel. Check with your doctor before buying a mouthwash, as many can cause burning pain if your child has mouth sores.
- To care for babies' and toddlers' mouths, wrap a soft cloth around your finger and gently wipe the teeth and gums with the mouth rinse. Soft oral swabs can also be used to apply the rinse to your child's mouth. (Oral swabs are available in drug stores.)

Fatigue

Many children with cancer have fatigue during and after treatment. Your child may describe fatigue as feeling tired, weak or even sad. Many things can cause fatigue, such as treatment, low blood counts, poor nutrition, fever, pain and worry.

Keep the healthcare team informed about fatigue. It's possible your child may need medicine, a nutritional supplement or a blood transfusion.

These tips may help with fatigue:

- Make sure your child gets extra sleep and rest. Encourage frequent naps.
- Try to have a regular bedtime routine.
- Offer healthy foods every few hours when your child is awake. Try to make each snack as nutritious as possible.
- Avoid caffeine (cola, coffee, tea).
- Have your child exercise a little each day. Being active, even if it's only gentle exercise such as walking, will help relax your child and may boost the appetite.
- Help your child decide what activities matter most. Do the most important things before your child runs out of energy. Plan shorter trips and play dates.

Hair loss

Chemotherapy and radiation therapy can cause hair loss or thinning of the hair. Hair loss can happen anywhere on the body: the scalp, eyelashes, eyebrows, under the arms and pubic area. The loss may be gradual, or it may happen all at once.

Parents of young children are often more concerned than their child about hair loss. On the other hand, teens may have a very difficult time with losing their hair.

While there's nothing you can do to prevent hair from falling out, the loss is usually temporary. Hair grows back when the cancer treatments are done, or in some cases, when the treatment becomes less intense. In many cases, the hair may be a slightly different colour or texture (curlier, thicker or thinner) than before the cancer treatment. In a few cases associated with high doses of radiation, the hair may not grow back.

These tips may help:

- Talk about the chance that your child's hair will fall out, so that there will be time to prepare.
- Ask your child about what to do. If your child agrees, you might cut the hair short to help ease the transition. Some children choose to shave their heads completely to avoid dealing with the gradual hair loss.
- Offer your child the chance to wear a hat, bandana, scarf or wig. Help them choose fun styles to express themselves.
- Have your child's picture taken with the hair as it's usually worn. If your child decides to wear a wig, the hairstylist can use the picture to help shape it. Keep a snippet of your child's hair to help match the colour and texture.
- Use a mild shampoo and a wide-tooth comb.
- Avoid harsh, damaging products containing bleach, peroxide, ammonia, alcohol or lacquer.
- Avoid using hair dryers and electric curlers.
- Protect your child's scalp from sun and cold.
- Talk to your child about how to handle teasing from other children. For a child returning to school it may help to have the teacher or someone from the hospital talk with the class about the child's hair loss beforehand. Teachers may be able to help in different ways, such as allowing the whole class to wear hats in school.

Infections

Treatments such as chemotherapy and stem cell transplants can lower the number of white blood cells (*leukocytes* and *neutrophils*) in the bone marrow. Leukocytes are a key part of the body's immune system and defend the body against viruses. Neutrophils surround and destroy bacteria in the body to keep a person well.

Your child's white blood cell count will be checked often during treatment. A drug to fight infections (an *antibiotic*) may be prescribed if the healthcare team thinks that your child is at risk of infection. If the white blood count becomes too low, your child's treatment plan may be changed.

Children who have had stem cell transplants are at very high risk of infection. They are isolated in a very clean room. They may not be able to have many visitors, and strict cleaning procedures will have to be followed.

Call your healthcare team – Signs of infection

- a fever of 38°C (100.4°F)
- white patches or coating in the mouth
- unusual sweating, especially at night
- diarrhea
- a burning feeling when urinating
- a severe cough or sore throat
- chills

If your child has any signs of infection, call the healthcare team right away. Talk to the healthcare team before giving your children any medicine to relieve a fever.

These tips may help prevent infection:

- Make sure your child washes their hands often during the day, especially before eating and after going to the bathroom. Carry a small bottle of hand sanitizer to clean hands when you can't get to a sink.
- Encourage your child not to share cups, eating utensils or toothbrushes.
- Avoid crowds and have your child stay away from anyone who has a cold, the flu or an infectious disease.
- Get your child to use cuticle cream or cuticle remover instead of tearing or cutting the nail cuticles.
- Have your teen use an electric shaver instead of a razor to prevent cutting the skin.
- Make sure teens don't squeeze or scratch pimples.
- Clean any cut or scrape right away with warm water and soap.
- Avoid using hot water when your child is bathing or showering. Hot water dries out the skin. When drying off, gently pat the skin dry rather than rubbing it briskly.
- Use a moisturizer or oil if your child's skin becomes dry or cracked to soften it and help it heal. The healthcare team or pharmacist can suggest one.
- Remind your child to clean the anal area gently but thoroughly after a bowel movement. Moistened wipes instead of toilet paper may be helpful.
- Check with the healthcare team before your child has a vaccination or flu shot.
- Avoid contact with children who have been recently immunized with "live virus" vaccines such as chicken pox, polio or measles.
- Don't let your child empty cat litter boxes or clean pet cages. Stool and urine from animals can carry germs that can be spread to your child.

Mouth sores

Mouth sores are a common side effect of chemotherapy and radiation therapy. They often occur in both the mouth and throat and can be very painful. If your child has mouth sores, pain medicine may help with eating and drinking.

To make eating easier, and to help prevent more pain or irritation, you can:

- Offer soft or moist foods that are easy to chew and swallow, such as:
 - > pudding, yogurt, custards or gelatin
 - > hot cereals (cooled to room temperature) or dry cereal soaked in milk
 - > soft fruit and well-cooked vegetables
 - > soft casseroles, macaroni and cheese or eggs
 - > baby foods or puréed meats
- Avoid food or drinks that can irritate the mouth, including: citrus fruit or juices, spicy or salty foods, and rough, coarse or dry foods (crackers, dry toast).
- Serve foods at room temperature. Hot or cold foods may irritate the mouth and throat.
- Make every bite count by giving your child food and drinks that are high in calories and protein. Liquid nutritional supplements or milkshakes are also good options if your child is eating less.
- Have your child rinse after every meal with a mouth rinse recommended by your doctor or dietitian.
- Use cotton or glycerin swabs (available in drug stores) to clean teeth and help remove pieces of food from the mouth.

- Talk to your doctor about prescribing pain medicine or anesthetic cream for the mouth sores if your child is in pain. To make eating easier, put the anesthetic on the gums before meals.
- Try a lanolin lip ointment if your child's lips are cracked and irritated.

Nausea and vomiting

Chemotherapy and radiation can often make children feel nauseated or throw up (vomit). Sometimes, just the thought of having these treatments or being in the hospital can make children feel sick.

It's often easier to prevent nausea than to treat it once it happens. Your doctor can prescribe anti-nausea medicine (called an *anti-emetic*) and may direct your child to take it before chemotherapy or radiation therapy and for a few days after. Different drugs work for different children, and your child may need more than one drug to feel better. Work with the healthcare team to find the drug or drugs that work best for your child.

You can do other things to help prevent and manage your child's nausea and vomiting:

- Offer bland, starchy foods to absorb stomach acid. An empty stomach can make your child feel sicker. Your child can nibble on dry foods like crackers, toast, dry cereals or bread sticks after waking up and every few hours during the day.
- Offer easy-to-digest foods, such as soup broth, clear liquids, soda crackers, toast, rice, pretzels, dry cereals, gelatin or arrowroot cookies.
- Offer lots of fluid between meals to keep your child hydrated and to dilute stomach acid. Have your child drink 30 minutes before the meal rather than with the meal. You can give flat ginger ale, water, diluted juices, sports drinks or drinks that

replace electrolytes that are made for children. Cool liquids may be easier to drink than very hot or very cold liquids. Sucking on ice chips may also help. **Alert: choking hazard for young children**

- Avoid foods that are acidic, spicy, strong-flavoured, sweet, greasy or fried, or have a strong odour.
- Keep your child away from the smell of cooking and food preparation.
- Serve food at room temperature or colder.
- Give your older child a hard candy to suck on to get rid of bad tastes in the mouth. **Alert: choking hazard for young children**
- Distract your child's attention by watching TV, reading or playing games so they don't notice any nausea as much.

Call your healthcare team – Vomiting and dehydration

Vomiting can lead to dehydration (loss of fluids in the body). Some common signs of dehydration include:

- dry skin or mouth
- no tears when crying
- infrequent urination or small amounts of dark-coloured urine

Call the healthcare team if you think your child might be dehydrated or if your child can't stop vomiting or if vomiting continues more than 24 hours after treatment, even if your child is taking anti-emetics as directed.

Skin changes

Cancer treatment can irritate the skin:

- *Radiation therapy* can cause a reaction that is like sunburn. The severity of the reaction depends on the area being treated and your child's skin type. Some children have no skin problems at all.
- *Chemotherapy* drugs can cause rashes, redness, itching, peeling, dry skin and acne. Some drugs can also cause changes in skin colour or nail changes.
- *Biological therapy* can cause redness, itching, dryness and peeling near the site of the injections. Lumps can form under the skin at the site of the injections as well. These usually go away on their own after treatment is finished.

Some cancer treatments can also make the skin very sensitive to the sun.

These tips may help with skin changes caused by **radiation therapy**:

- Follow the bathing instructions suggested by the radiation therapy team.
- Ask a member of the radiation therapy team to recommend products that will not irritate the skin or interfere with treatment. Do not use any powders, creams, perfumes, aftershave, deodorants, body oils, ointments or lotions in the treatment area unless approved by someone on your child's team.
- Use an electric shaver rather than a razor to prevent cutting the skin in the treatment area. If your teen does cut or scrape the skin while shaving, talk to the radiation therapy team.
- Do not put anything hot or cold (such as heating pads or ice packs) on the area being treated.
- Make sure teens don't squeeze or scratch pimples.

- Protect skin in the treatment area from the sun with clothing or a hat. Sunscreen may irritate the area being treated and should be used only after treatment is finished and after any skin-related side effects have gone away (likely 4 to 6 weeks after treatment).
- Protect treatment areas from rubbing, pressure or irritation. Cotton or silk clothing is less irritating on the skin than harsh fabrics such as wool and corduroy. Avoid tight clothing of any kind.

These tips may help with skin changes caused by **chemotherapy**:

- Wash your child's skin often to lower the risk of skin irritation and infections.
- Have your child bathe in warm water instead of hot. Hot water dries out the skin. Gently pat the skin dry rather than rubbing it briskly.
- Use a moisturizer or oil to soften the skin and help it heal if it becomes dry or cracked. Look for a moisturizer that doesn't contain alcohol. The healthcare team or pharmacist can suggest one.
- Use cuticle cream or cuticle remover instead of tearing or cutting the nail cuticles.
- Have your teen use an electric shaver rather than a razor to prevent cutting the skin. If they do cut or scrape the skin, clean the area at once with warm water and soap.
- Make sure teens don't squeeze or scratch pimples.
- Protect your child's skin from the sun with a wide-brimmed hat and clothing that covers their arms and legs. Apply sunscreen lotion with a sun protection factor (SPF) of 30 or higher when going outside, or use zinc oxide to fully block out the sun.

These tips may help with skin changes caused by **biological therapy**:

- Have your child bathe in cool water using oatmeal or oil soap. Or add baking soda to bath water.
- Talk to your child's healthcare team about moisturizers and creams to relieve any itchiness. They may also prescribe medicines to help.

Talk to your child's healthcare team if your child has a severe rash or is very itchy.

Taste and smell changes

Cancer treatments can change your child's senses of taste and smell. Familiar foods may taste different or unappealing. The smell of food cooking may make your child feel sick.

These tips may help:

- Offer a variety of foods. Your child may develop new favourites.
- Offer other sources of protein, such as chicken, turkey, eggs, dairy products, fish or seafood. Some children find that red meat tastes bitter or metallic.
- Try using plastic instead of metal cutlery to decrease the metallic taste.
- Offer tart foods – like citrus juices, pickles or cranberry juice – to decrease metallic taste. Don't offer tart foods if your child has a sore mouth.
- Try barbecuing or cooking outside to reduce kitchen odours.
- Offer foods at room temperature. Do not offer steaming-hot foods, as the steam vapours increase the foods' smells.
- Try different spices and seasonings to enhance the flavour of food. Some children find they have more taste for sweet or salty foods.
- Encourage your child to rinse their mouth often to help get rid of bad tastes.

Weight gain

Sometimes, children gain too much weight during cancer treatment. It may be that they're less active than before or are eating too much for comfort or boredom. Some medicines such as steroids can also lead to weight gain. To help control weight gain, you might limit the amount of salt and lower the calories, fat and sugar in their diet.

Limit salt

Steroids can raise salt (*sodium*) levels in the body, causing water to build up, often in your child's ankles or face. The extra water can also cause weight gain. To decrease salt in your child's diet:

- Get rid of the salt shaker at the table.
- Limit high-salt foods, including salted popcorn, pretzels, corn chips, salted nuts, French fries, canned soups or gravy, store-bought or take-out meals, soy, steak and Worcestershire sauce, sea salt, garlic salt and celery salt.
- Use smaller amounts of condiments like ketchup and relish.
- Try unsalted butter or margarine.
- Limit salted crackers, prepared rice, pasta or potato mixes or canned pastas.
- Watch out for high-sodium cereals. You may not think your child's favourite cereal has a lot of salt, but check the label.
- Limit pickles, pickled vegetables and canned vegetables.
- Limit portions of most cheeses. Examples include processed cheese, cheese spreads or sauces, cottage, feta, Parmesan, Swiss, cheddar and blue cheeses.
- Limit high-sodium meats, including deli meats (especially bologna), pepperoni and ham, bacon, sausage and hot dogs.
- Limit canned beans, battered fish, pickled meat or eggs.

Lower the calories, fat and sugar

You can help prevent weight gain by providing healthy meals and snacks, and preparing food in healthy ways:

- Avoid food or snacks that are fried or high in fat or sugar.
- Offer lots of high-fibre foods, including fruit, vegetables and whole grains. These can help make your child feel full longer.
- Offer lower-fat milk, yogurt or cheese products.
- Choose leaner cuts of meat or choose legumes, egg whites and tofu.
- Trim visible fat or skin from meats.
- Bake, broil or barbecue food instead of frying.
- Limit added fats like butter, mayonnaise, salad dressings and sauces.
- Use spices or seasonings instead of high-fat sauces, butter or gravy.
- Encourage your child to drink water. This can help the stomach feel full. Limit the amount of soft drinks, juices, punch, sweet tea or lemonade.
- Serve healthy, nutritious snacks that are low in fat, sugar and salt if your child is hungry between meals. Try unsalted pretzels and plain popcorn, sliced fruit and plain, low-fat yogurt, raw vegetables and low-fat, low-salt dip, low-fat cheese and Melba toast.

Along with the tips above, try to keep portion sizes appropriate to your child's age and make sure the rest of the family sets a good example. It's hard for children to eat low-fat, low-sugar foods when the rest of the family is feasting on hamburgers and fries.

You can also be as active as possible and encourage your child to be active. This will help limit weight gain and will help keep your child's bones and muscles strong.

Weight loss

Children can lose weight during cancer treatment. The cancer itself can interfere with getting enough nutrients, while the physical and emotional side effects from cancer treatment can make children feel sick or find food less appealing. This can lead to loss of appetite and weight loss.

Make every bite count if your child is losing weight. You can:

- Offer small meals and snacks frequently throughout the day. Remind your child to eat for fuel and energy – even if they are not hungry. Setting regular times for meals and snacks may help.
- Have high-calorie, high-protein snacks prepared ahead of time so that you can give them immediately if your child asks. A snack should consist of at least two food groups. Try cheese and crackers, grapes and cheese, granola and yogurt, yogurt and fruit, a peanut butter sandwich, hummus and pita, cottage cheese and fruit, or veggies and crackers.
- Make beverages count. Instead of low-calorie drinks like water, clear broth, tea or diet pop, offer higher-fat milk, milkshakes, soups and juices. Offer water between meals rather than at meals to make your child feel less full at mealtime.
- Make eating pleasant and fun. Never underestimate the power of novelty, especially for young children. Try different coloured foods, use garnishes, try new seasonings and let your child help prepare meals, if up to it. Cut sandwiches and pancakes into shapes using large cookie cutters.
- Don't force your child to eat. Try to avoid battles over food.
- Offer less of low-nutrient foods such as candy, chocolate and chips. These foods can make your child feel full without providing the nutrients your child needs.
- Offer chewing gum, which can stimulate and help increase the appetite. **Alert: choking hazard for young children.**

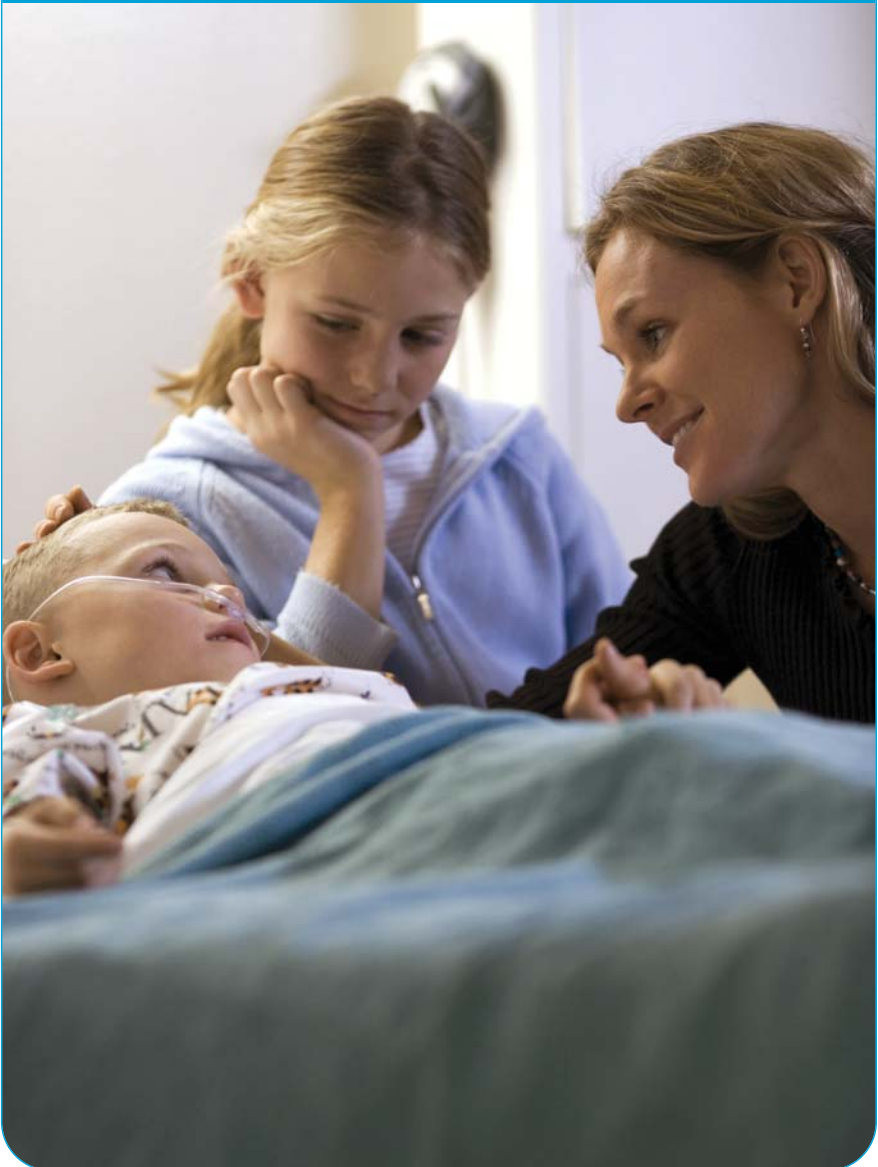
- Avoid “light”, diet or low-fat foods.
- Choose higher-fat meats such as dark chicken, regular ground beef, wings or ribs.
- Fry foods using a vegetable oil such as canola or olive oil.
- Encourage light exercise or walking outside before meals, if possible. More activity just before eating and fresh air can stimulate the appetite.

Weight loss can sometimes get serious. If so, your child’s doctor or dietitian may suggest *nutritional supplements*, which are rich in calories, protein, vitamins and minerals. They are available as drinks, puddings, powders and bars. They can help give your child extra nutrition when they cannot eat enough food. Or, if your child cannot get the calories and nutrients they need by eating and drinking, then the healthcare team can suggest using a feeding tube to deliver nutrition directly to the stomach or blood.

Learn more about nutrition for children with cancer

For more detailed information about nutrition, eating-related side effects and how to manage them, you may find our booklet *When Your Child Has Cancer: A guide to good nutrition* useful.

Pain



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Many parents would rather take on their child's pain than have their child suffer. While this isn't possible, there are ways to prevent, lessen and relieve pain from cancer and cancer treatments. This chapter talks about:

- helping your child communicate about pain
- managing pain or discomfort

Helping your child communicate about pain

As a parent, you probably know if your child is in pain. But your child's healthcare team needs to understand your child's pain in order to treat it. They will need to know:

- whether the pain is sharp, dull, achy, tingling, cool or hot
- whether your child has had this type of pain before
- where the pain is located, and if it spreads to other body parts
- how long the pain lasts
- what makes it start and what makes it stop

You can help your child learn how to use a *pain scale* to communicate about pain and its intensity. For example:

- If your child understands the order of numbers, ask whether the pain is a number from 1 to 10, with 10 being the worst possible pain the child can imagine and 1 being no pain at all.
- Younger children may understand the idea of a pain scale using ideas. For example, "Does it hurt a little, medium or a lot?" or "Does it hurt the same, more or less than when you ..."
- Some pain scales show different facial expressions, from happy to very upset. Your child can point to the face that shows the right level of pain.

For very young children who can't speak yet, the healthcare team may use other methods to tell how much pain your child is in. For example, the FLACC pain scale takes into account a child's facial expression, body posture and activity level, whether and how much they cry and whether they are easily calmed.

Ask your nurse or child life specialist to help you find pain scales that will work best for your child.

Every child is unique

Not all children with cancer have pain. If they do, each will feel it in their own way. Many other factors, including fear, can affect how a child reacts to pain.

Managing pain or discomfort

Pain medication

Pain medicine can help manage your child's pain. The type and amount of pain medicine, and how it's given, will depend on the type of pain, your child's weight and whether your child can take medicine by mouth.

You may think that it's best for your child to avoid taking pain medicine for as long as possible. In fact, it's always better to try to prevent pain from starting or getting worse by treating it right away. Treating pain right away may also mean your child will need a lower dose of a pain reliever than if you wait until the pain gets bad. Different pain medicines take different lengths of time to work, from a few minutes to several hours. If your child waits too long to take pain medicine, the pain may get worse before the medicine helps.

Some parents worry that taking pain medicine, especially medicines like morphine, can lead to addiction. Taking pain medicine regularly for pain control is very different from addiction. The healthcare team will make sure your child has just enough pain medicine to keep the pain under control.

Pain medication during tests and procedures

Some medical procedures are uncomfortable or painful. For some tests, your child may need to remain still for as long as an hour. This can be a challenge for many older children, and impossible for babies and younger children. You and your child's healthcare team can do many things to make tests and other procedures easier, less painful or less frightening, including giving the following:

- ***Local anesthetics*** can numb the skin and tissues. "Magic" creams that numb the skin can be used so that your child can't feel needle pricks. Once the surface of the skin is numb, other numbing medicines can then be given with a needle. The numbing medicine may burn a little bit, but after a couple of minutes, the tissue will feel numb all the way down to the bone.
- ***Sedatives*** are medicines that may make your child feel calm and sleepy. With sedation, your child relaxes and may not remember having the test done.
- ***General anesthetic*** makes your child go completely to sleep. Your child will not feel pain, move, or remember the test or procedure.

With general anesthesia, there is a small risk that your child's breathing or heartbeat can slow. Your child will be watched closely on a heart monitor both during and after the test until fully awake. A doctor trained to give general anesthetic will watch your child during and after the test. Your child will not be able to eat solid foods or drink liquids for a few hours before the procedure.

Other ways to relieve pain

Fear of the unknown can make pain much worse. That's why it's important to talk about medical tests and procedures with your child. If children understand what is going to happen, where it will happen, who will be there, what it will feel like, and so on, they will be less anxious and better able to cope. Letting your child decide the best way to control any pain during procedures can also help. Some children prefer to cope by watching and participating as much as possible in the procedure, while others prefer to be distracted.

To prepare your child for a possibly painful test or procedure:

- Wake your toddler up before a painful procedure. Tell your toddler what will happen just before the treatment or procedure. Use simple words, pictures or books to explain what will happen. Ask your child life specialist for help explaining procedures.
- Explain each step in the procedure, including what your child will see, hear, smell, taste or feel. Talk about ways to help cope during the test. Many children feel comfortable rehearsing the steps of the procedure, or acting them out with a doll or model.
- Encourage your child to ask questions and answer them as honestly as you can.
- Meet the person who is going to do the procedure.
- Tour the room where the procedure will take place beforehand (if possible).
- Watch a DVD or video, play a video game or look at a *photo preparation book* about the procedure.
- Encourage your child to make as many choices as possible about the procedure. For example your child may be able to decide whether to sit or lie down, which arm or leg will be used for painful injections, whether or not to use numbing cream, what coping strategy to try and so on.

- Reassure your child that you will be there during the procedure.
- Ask the child life specialist or psychologist to help your child prepare and deal with fears.

“ *My son became extremely angry when he had to deal with treatments that were painful. He hated getting his GI tube replaced. He would lash out at me, punching, biting, screaming and yelling. I asked the hospital psychologist to come in and help him deal with his anger. She used toy soldiers to map out his anger for him so that he could talk about what he was feeling and how to cope with it. That really helped.* ”

To help your child cope during a painful procedure:

- Encourage your child to watch and participate as much as possible in the procedure (only if this is the way your child prefers to cope).
- Try distractions such as music, television or reading (if this is possible) if your child prefers not to focus on what is happening.
- Distract babies with colourful moving objects, rocking, stroking, patting, using a soother or bottle, playing music or talking or singing in a soothing voice.
- Distract toddlers and preschoolers by showing picture books or videos, telling stories, singing songs or blowing bubbles. Hugging a comforting object like a blanket or stuffed animal may help.

“ *Our son loved rocks and minerals, and he made the decision to bring a crystal with him and hold onto it during treatment.* ”

Some healthcare professionals can teach you and your child relaxation techniques. Some techniques that may help during procedures are:

- listening to slow, quiet music
- taking slow deep breaths
- meditation that focuses on an object, sensation or phrase
- imagery where the child imagines or remembers a place or activity that they like to do

“ *To help our son deal with needle pokes and discomfort, I thought back to the most uncomfortable time in my life – labour and giving birth – and how I dealt with it. He learned to breathe deeply and focus on his breath.*

After the procedure is over

Praise or reward your child for using a coping strategy after the procedure is over – not for going through something painful. If you focus on and reward the fact that your child had to do something awful, you send the message that your child has very little control over the situation and can't do much to make life easier and better.

By focusing on your child's strengths and appropriate behaviour, you are doing three important things:

- giving the message that your child is strong and has an important, active role to play in treatment
- raising self-esteem by praising your child for getting through a difficult task
- finding out what worked and what to remember for next time, which will give your child confidence that the strategy can be used again successfully

You may need to make note of the smallest positive behaviour, such as taking a breath, listening or using words. For example, you might say, "I'm so proud of you. You did a really good job of focusing on your breathing and cooperating with the doctors during the spinal tap. Now we're done with that sort of stuff for today – let's go to the play room or watch a DVD."

Staying in the Hospital



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Most children with cancer will have to stay in hospital at some point. Coping with hospital stays can be a challenge for all members of the family, especially if you're travelling away from home for treatment. This chapter talks about the many things you can do to:

- help your child cope with hospitalization
- make hospital stays easier on parents
- make hospital stays easier on siblings

Helping your child cope with hospitalization

Children often need to be in the hospital for intensive treatment soon after they're diagnosed with cancer. They may be in the hospital for diagnostic tests, surgery, ongoing cancer treatment and side effects from treatment.

Some hospital stays may be a matter of a few days, while others could be several months.

Being in the hospital is often scary for kids, especially at first. For one thing, it's a whole new world to learn about – new people and strange machines, procedures and routines. One of the hardest things for children is being separated from their parents and siblings. Fortunately, most hospitals and treatment centres help children with cancer spend as much time with their family as possible. It's often possible for parents to stay with their kids overnight, except in some situations.

Encouraging cooperation at any age

Children of any age will often cooperate more if they are allowed to make choices that do not cause problems with their treatment or care. This can help a child feel in control. But don't offer a choice when one doesn't exist. Be careful not to add the word "okay?" after a statement. If you say, "It's time for your procedure, okay?", the word "okay" implies there is a choice. Children are quick to tell you it's not okay.

"During his treatments, we gave our son as much control as we could. The nurses and oncologists would give him choices about whether to have blood work in the morning or in the afternoon, and what to eat. They were small things sometimes, but they helped him feel involved in the decision-making process. Today, my son's school principal tells me she's never met such a diplomatic child."

Babies and toddlers

Babies (birth to 12 months) rely on their parents and familiar adults for food, comfort, play and care. They trust in people and things that are familiar. Toddlers (1 to 2 years) want and need to be able to do some things by themselves. They tend to think that they make things happen. They may think that they're in the hospital because they were bad and are being punished.

Babies and toddlers don't want to be separated from parents and caregivers. Most children, especially younger ones, want their parents to spend as much time as possible with them. Usually, you can visit any time and can sleep at the hospital, in your child's room or nearby.

Staying in the hospital is often upsetting for babies and toddlers because they may be scared of strangers and medical procedures. They're usually unhappy when their familiar routines change. They need to feel safe. Toddlers need to feel some sense of control.



I had just weaned our son when he was diagnosed with cancer at 12 months. Our team suggested that it might be a good idea to re-establish breast-feeding, both for his comfort and nutrition. That idea worked really well.

These tips may help make a hospital stay easier on your baby or toddler:

- Rock or hold your baby when in the hospital. Use gentle touch and massage to comfort your baby. Talk and play games, like peek-a-boo.
- Bring a familiar object such as a toy, blanket, stuffed animal or pacifier to help comfort your baby or toddler. Keep these objects nearby, especially during medical tests.
- Make your baby's crib or toddler's bed a "safe zone". Ask that any procedures be done in the treatment room and not in the crib or bed.
- Use basic sign language with your child to help them communicate what they need – learn and teach the signs for *eat, drink, tired, scared, sick* and so on.
- Share information about your child's comfort items and activities with members of your child's healthcare team. This can help them bond with your child.
- Limit the number of people and voices in the room.
- Continue or start feeding, bedtime and bath time routines, like rocking, reading and singing.
- Tell your toddler where you're going and when you'll be back if you have to leave. When you are gone, leave something of yours, like your shirt or a picture of you, for your toddler to keep until you return.
- Give your toddler a job to do such as holding bandages or putting a toy away.
- Let your toddler play and be in control of the game or activity.

- Let your toddler play with favourite toys.
- Let your toddler know that it is all right to feel mad or sad. Provide safe ways to express anger and other feelings such as moulding clay or play dough, or finger painting.
- Set the same limits and provide the same discipline with your toddler that you would normally use.

Preschoolers (3 to 5 years)

Preschoolers want to do – and take pride in doing – things on their own. Children this age are becoming more and more independent. While they may not cry when you leave the room, they still need lots of hugging and physical closeness. Normal childhood fears such as a fear of the dark or fear of going to sleep may increase at this time and make hospital stays even more challenging.

At this age, children can see the hospital and treatment as punishment for something they did wrong.

These tips may help your preschooler adjust to being in the hospital:

- Stay with your child as much as possible. When you have to leave, tell your child when you'll be back and leave behind something comforting to keep – like a photo of you or a favourite toy.
- Tell your child what will happen a little while before the treatment. Use simple words, pictures, dolls or books to tell your child about what will happen.
- Let your child play with doctor kits and safe medical supplies, like a blood pressure cuff. This can ease fears about treatment. A child life specialist can help.
- Give your child a job to do such as getting pajamas out or folding clothes after changing.

- Try to keep normal routines like getting dressed, mealtime and brushing teeth. Let children do as much as possible on their own.
- Give your child time to adjust to new changes. Use play to help your child show feelings.
- Find out if the hospital has a playroom or special programs. Playrooms often have toys, games, arts and crafts supplies and CD players, giving children a chance to play with each other in much the same way they do with their friends at home, daycare or school. Some playrooms include outdoor spaces.

School-age children (6 to 12 years)

School-age children take pride in being able to do most things by themselves. Their friends are becoming more important and they may worry about missing school. Being told what to do or helped all the time in the hospital, and missing their friends, makes staying in the hospital tough on this age group.

These tips may help your school-age child settle in to a hospital stay:

- Give your child a job to do such as gathering clothes for you so that you can take them home to wash or picking out some artwork to send to a grandparent or friend.
- Encourage your child to get to know the healthcare team. Share their names and let your child know that it's okay to ask them questions.
- Decorate the hospital room with favourite family photos or drawings, and bring in special books, CDs or toys from home.
- Find out whether you can have “family nights” in your child’s room. Some families have a weekly pizza or movie night in the child’s room during long hospital stays. This can help siblings as well.
- Find out if the hospital has a playroom or special programs. Playrooms often have toys, games, arts and crafts supplies and

CD players, giving children a chance to play and talk with each other in much the same way they do with their friends at home or in school. Some playrooms include outdoor spaces.

- Ask the child life specialist about ways to “normalize” the hospital experience and ways to keep stress and anxiety to a minimum.
- Send pictures of your child having treatment to the school. Some families fill photo albums with pictures that are shared with the classmates.
- Ask the hospital whether there are any options for your child to keep up with school work (if possible) during a lengthy hospital stay. Some children’s hospitals may have teachers affiliated with the Board of Education as part of their healthcare teams.
- Help children keep in touch with friends by letting them write and call when possible. Let friends visit when your child feels well enough.
- Encourage classmates to keep in touch by sending notes, phoning, texting, e-mailing, sending class pictures or making a scrapbook. Some hospitals have equipment that allows children to interact with their classmates in the classroom.



My son missed half of kindergarten and half of grade 1. We had pictures of all the kids in his class, and he got get-well cards from the kids, so he could match the pictures to the cards and feel as though he knew the children and his class. When he returned to grade 1, it didn't take long for him to fit right in.

Teens

Teens want to be independent from the adults around them – they are starting to see themselves as individuals in the world. As they start to think and act for themselves, their friends become even more important. Teenagers are very concerned about how others see them. They are desperately trying to be like their friends, and illness and treatment force them to be different.

At a time when they are normally starting to do more on their own, cancer makes teenagers rely on you more. This can frustrate them. They may let you know that they're unhappy – loudly and often. They may rebel in many ways, break hospital rules, miss outpatient appointments or refuse treatment.

Even in the hospital, there are ways you can respect your teenager's growing independence, privacy and connection to friends:

- Allow your teen to make choices whenever you can.
- Involve teens in the treatment plan and in conversations with the healthcare team.
- Encourage teens to look after themselves – bathing, dressing, grooming, eating – as much as possible.
- Give your teen many chances to talk about physical and emotional changes. At first, your teen may not seem interested in talking. A child life specialist can offer strategies to encourage self-expression and coping.
- Tell your teen that having feelings about illness and treatment is okay.
- Let teens wear regular clothing, as opposed to hospital gowns and pajamas, whenever possible.
- Let your teen decorate the hospital room with favourite photos or posters and bring in special books or CDs.

- Ask if the hospital has programs and special offerings for teens, such as magazines, video games, movies, games, crafts and entertainment events.
- Respect privacy – around things like the bathroom, phone calls, e-mail – whenever possible.
- Let teens be active in social and school activities, whenever possible. Encourage them to continue with some schoolwork when well enough to do so.
- Allow some private time with friends when they come to visit at the hospital.

Making hospital stays easier on parents

Having a child in hospital can be very stressful. In addition to having a sick child, parents must also cope with the unfamiliar setting, being away from other children and family members, and balancing household chores and work responsibilities. Parents may need to take time off work, at a time when their expenses (for things like travel, parking, hotels, childcare or meals) increase.

Yet in some ways, some parents may find it reassuring to know their child is being looked after in the hospital, especially if the child's symptoms or disease have been hard to manage at home, or it has taken a long time to get a diagnosis.

“ *Things seemed very overwhelming in the beginning, but the support of all the staff and nurses made things much easier.* ”

It's very important for parents to remember to take care of themselves, especially during more stressful times.

“ *Never, ever forget about taking care of yourself. It's so easy not to eat properly, not to go for that walk. Parents have to remain healthy to be strong for their kids. My husband and I went for runs, together or on our own, every day. When my son was in a clean room for his stem cell transplant, we would take turns so that one person could go eat lunch, go for a walk and get some fresh air.* ”

Things usually look better in the morning

If you've managed to get some sleep, that is. If the hospital bed is uncomfortable, or if the hospital can't provide you with a bed, you may want to get an air mattress.

“Getting a good night's sleep makes a huge difference to how you can cope during the days. We brought a queen-sized air mattress with an electric pump and comfortable pillows. It was always packed and ready to go in our hospital kit.”

These tips might help make a hospital stay easier on you:

- Find out what the hospital offers for patients and their families. Some cancer centres provide snack foods, such as juice, yogurt, popsicles, bread and cereals. Many have kitchen areas with a refrigerator, kettle, toaster and microwave, and showers for parents.

“ *Get to know the hospital schedule: which refrigerators are available to use and when the clean linens are distributed so you can get an extra pillow or blanket if you need one.* ”

- Find out about where to find parking, food, general amenities and what's in the neighbourhood. The hospital may provide information, or you can ask someone on the healthcare team, or other parents of children in the hospital.

- Talk to other parents in the hospital. They may be able to provide support and give you useful information about services and programs.

“ *I would tell other parents to talk to the parents in the clinic. Don't be shy. Find out if their child has the same cancer as yours. Find out what you can expect down the line. Find out about services they have used that might help you. Try to have other kids with cancer talk to your child as well. In short, surround yourself with people who are going through the same thing.*

- Prepare yourself for a lot of waiting. Find ways to make waiting during clinic visits or while in the hospital less frustrating. Take something to read or do while your child is asleep or doesn't need your attention.
- Find ways to take breaks. If you can, get friends and family members to spend some time with your child so that you can go out every so often. Hospital volunteers may also be able to stay with your child for a short while.

“ *If you have relatives and family close by, get them to come in and keep company ... Do anything you can do to get people to help.*

- Nurture your relationship with your spouse or partner. Find time to talk and be together.

“ *At the beginning of our son’s cancer treatment, we made a pact that one of us would always be in the hospital room with him. But we soon realized that we needed some time together. Our parents would come in and babysit and send the two of us out for a dinner date.*

- Keep a journal or binder to write down what happens during the day – tests, any side effects to medicines and so on.

“ *We kept a special binder that had a detailed copy of the treatment plan and protocol, our child’s last discharge summary, appointment slips, blood counts and the names and contact information of the healthcare team.*

- Bring your phonebook, PDA or cell phone, so when you need to make calls, you have all the phone numbers you need on hand. (Make sure it’s okay to use a cell phone in the hospital.)
- Have a “hospital kit” with the essential items for your child and your own comfort packed and ready to go.

Hospital kit

Need to have

- your child's provincial healthcare card
- your child's hospital ID card (if your child has one from a previous visit)
- immunization records
- list of any medicines, and the amounts, that your child is taking
- braces, corrective shoes, crutches, glasses, hearing aid or other such appliances
- notepaper and pen
- regular medicines that your child needs to take during a hospital stay
- name, address and telephone number of your referring doctor
- name, address and telephone number of your family doctor

Nice to have

- comfortable clothes for everyday wear, for you and your child
- pajamas, bathrobe and slippers
- toothbrush and toothpaste
- comb and brush
- a few favourite games, toys, books, hobby materials
- school books, current school work and the name of your child's school and teacher
- any toys or articles that are important to your child
- your child's own pillows, blankets and a favourite toy
- books, games, snacks and so on, to keep you and your child occupied
- hot/cold gel pack to help manage pain
- headphones so that you or your child can watch TV or listen to music without disturbing other kids or parents
- phone cards to make local and long-distance calls
- small change for vending machines

Label all of your own and your child's items clearly. Be careful about bringing valuables of any kind, such as jewellery or large sums of money. Find out if the hospital allows MP3 players, cell phones and electrical appliances, such as hairdryers, radios or TV sets. Some of these items may interfere with medical equipment.

"We kept our hospital 'kit' packed and ready to go. It included our cooler and a portable DVD player. One of the best things we did was to buy a cooler that you can plug in. We filled it with water bottles and snacks, peanut butter and bread, whatever food we needed for the day. We also brought in our own kettle, mugs, coffee, tea and milk. Hospital food is expensive, so anything we could do to cut down on our spending helped."

"One of my best investments was a mini book light so I could read when the hospital lights went off."

Making hospital stays easier on siblings

Brothers and sisters of children with cancer can also find it hard when their sibling is hospitalized. Routines and family life will change. One or both parents may be away for extended periods of time. They may miss and worry about their sibling with cancer. They may be angry or upset about these changes and may act out to show their displeasure.

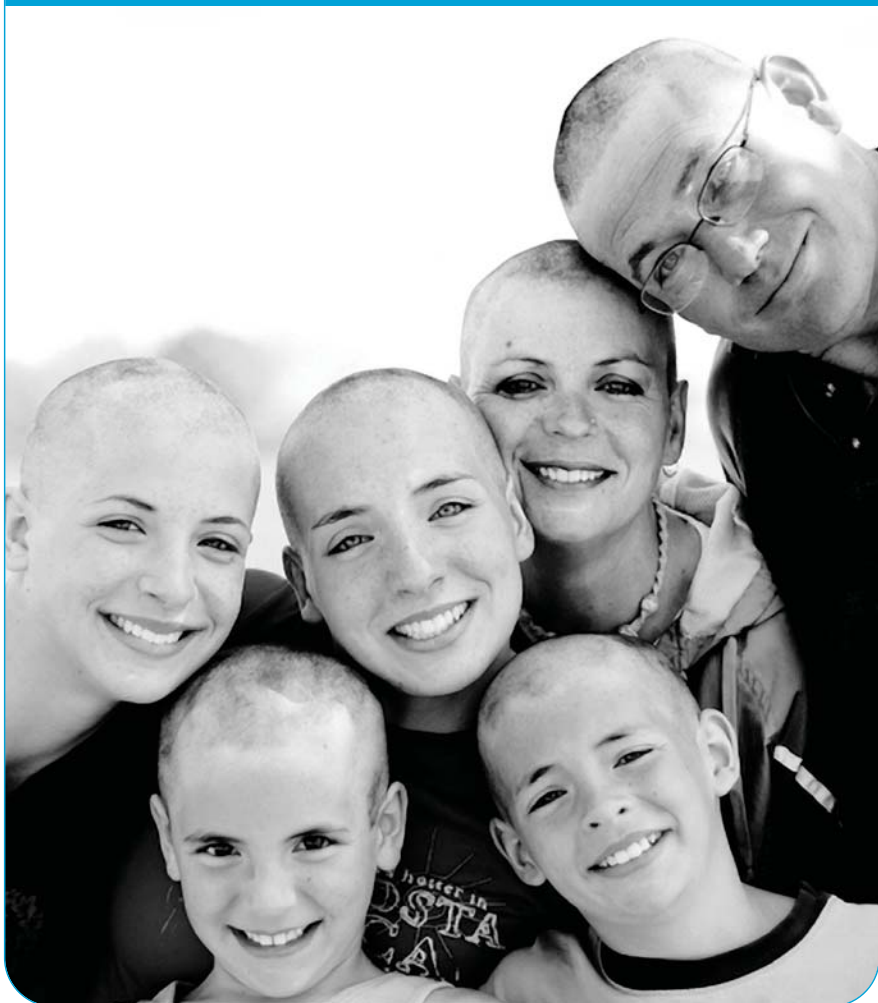
“ *My husband and I made the decision to be together throughout our son's treatment. That meant we had to be away from home a lot. Our 3-year-old daughter stayed with my parents when we were away. That was hard on all of us. The thing she knew was that she wasn't with us. She felt like she was being punished, and I think she's still bitter about that today. It's been hard, very hard, possibly the hardest on her.*

- Ask your social worker or child life specialist if the hospital offers any programs or services for siblings. Many hospital programs welcome the siblings of children with cancer and may even offer special activities or support groups for them.

- Do your best to keep siblings' routines as consistent as possible. For example, try to arrange for siblings to continue going to activities that are important to them. Family and friends are often more than willing to drive your children to lessons and other events.
- Let family members or close friends spend "special" time with your child who is well, providing attention and nurturing that you may not be able to give.
- Acknowledge to siblings that things have changed and might be difficult. Let them know that it's okay to be upset about changes, and that they can talk about them honestly.
- Try to plan special "protected" time with siblings - reading stories, playing in the park, going to the movies or out for dinner.
- Consider taking siblings along when travelling for treatment. Your social worker may be able to help with arranging accommodation for the family or tutoring for missed school.



Coping Within the Family



Photographed by John Fearnall ©, PhotoSensitive

A cancer diagnosis affects the whole family. It's not easy, but you can all cope with these changes. This chapter includes information on:

- cancer is a family affair
- your child's reaction to having cancer
- helping parents cope
- helping siblings cope
- when cancer is advanced

Cancer is a family affair

When a child is diagnosed with cancer, life changes for every member of the family. Everyone can feel anxious, uncertain, scared for the future, out of control and overwhelmed by extra responsibilities and demands on their time, energy and emotions.

- Children with cancer face big changes to school and their other activities. They may be more dependent on their parents and others. They may be anxious about medical procedures and tests, changed self-image and relationships and interruptions in their friendships and schooling.
- Siblings must also deal with the cancer, disruptions to their routine, and often conflicting emotions about the effects of the disease on their lives.
- Parents may need to renegotiate work schedules and deal with changes to finances.
- The entire family must deal with disrupted routines. It's hard to keep up with everyday activities and responsibilities while being with and caring for the child with cancer.

“ *My family took it very hard ... I was not the one asking for help ... I wanted to handle this as a family only. The staff helped me understand that they were there to help all of us. When I accepted we needed help, the psychologist and the social worker were there for us, especially with my youngest, who was being looked after all over the place and found it hard to be without her mother and older sister for weeks ... They gave me some advice, which I followed to the letter, and because of their advice, my family made it through this disease that turned us all upside down.* ”

Still, family life goes on. As the parent of a child who has cancer, remember that you are not alone. You can get help from many sources, including:

- your child’s healthcare team, which may include a social worker who can help you in dealing with your child’s illness
- friends and family members
- other parents of children with cancer
- support groups

Your child’s reaction to having cancer

Children’s feelings about having cancer are just as complex as adults. Children of any age may react to the diagnosis of cancer with emotions such as fear, anger and guilt.

Children may be afraid of being left alone, not knowing what is going to happen next and dying. Open and honest communication can help to ease a child’s fears.

They may be angry at themselves, at parents for “letting” this happen, or at anyone or everyone around them.

Children may feel guilty because they believe that the cancer is punishment for something they did or thought. They may also feel guilty for making the family sad. Let kids express their feelings and tell them no one thinks they did something wrong or blames them for getting sick.

Children may respond to the stress of being diagnosed with cancer by “regressing” or going back to an earlier stage of development. This means that a child may want to have a bottle again, may start wetting the bed, or want a soother or favourite blanket or toy that had previously been given up. These things may be comforting to a child and this behaviour will usually stop when the child starts to feel better or when the treatment ends.

Some children withdraw rather than express their feelings. Withdrawal can be a temporary way to start coping with strong feelings. But too much withdrawal may be a sign of depression. If you think your child may be depressed, talk to someone on your child’s healthcare team about what help is available.

Helping your child cope at home

There are many ways that you can help your child cope with feelings and with the many changes to daily life:

- Talk to your child openly and honestly about their fears. Only by talking about them can you help ease their fears.
- Tell your child it isn’t their fault, or your fault, that they have cancer.
- Let your child express any feelings of guilt they have and tell them that they’ve done nothing wrong – you don’t blame them for getting sick.
- Help your child learn the difference between having feelings (which is always okay) and acting on strong feelings in harmful or hurtful ways (which is not okay).

- Consider finding a group program for your child where they can meet other children going through the same things. In such a group, children with cancer are the same as everyone else and feel less alone.
- Come up with ways for children to release anger. They can mould clay, draw pictures, punch pillows, talk about it or ask for a big hug.
- Get professional help whenever you are concerned or have run out of ideas on how to handle emotional problems.
- Let your child live as normal a life as possible. Send them to school when they feel well. Have friends over and enjoy activities that were a part of life before cancer.
- Help your child find quieter activities to do (such as reading, drawing, painting or watching a movie) when feeling unwell or recovering from treatment.
- Take control of any incoming gifts. Too many gifts can make the child with cancer believe that things are much worse than they are and can make siblings jealous. Your child may also have a hard time when the gifts suddenly stop after treatment is over. Be open with family and friends if you think gifts are causing problems within the family.
- Give your child some control by offering choices when you can, such as coming up with some of the “house rules” or helping to plan meals and activities.
- Use the same rules and level of discipline as before the diagnosis. Children need consistency, structure and guidance from adults who are in charge. At the same time, be realistic and give yourself a break. You can't be a perfect parent all the time.



You have to let go of a lot of your parenting ideals. I swore I'd never let my children watch 12 hours of television straight, but some days that's all my son was up to. Do what you can to make your child comfortable and happy when he or she is not feeling well.

Helping your child cope with school

School is the major “normal” activity of children and teens. School is a place that frees children with cancer from hospitals and procedures, a place of fun, friendship and learning. Children need to understand that it's good to go to school when they can and that education is still important.

- Encourage your child to return to school after taking time off for tests and treatment. Children who have cancer need and like to be with others their own age.
- Help friends and classmates understand and make sense of your child's cancer by giving them some basic information about it. A member of the healthcare team may be able to help you and your child decide what information to give to your child's class.
- Let friends at school ask questions, and have someone knowledgeable answer them. A teacher who knows your child can help by learning a bit about your child's cancer and provide the information to schoolmates.
- Have assignments and materials sent home from the school when your child is not feeling well enough to go in.
- Consider a home tutor if your child is going to be away from school for some time. A tutor can help with keeping up with studies and make it easier to return to school.

Helping parents cope

When a child is sick, parents naturally feel they must do everything possible to help that child get well.

“ *While my child was sick, there was only him, him and him. I realised that the first 6 months of his treatment, I existed on adrenaline. I had to be strong and reassuring for him, even if I didn't feel it on the inside. I had the impression of being a spectator to this event – I was programmed to save him and give him all the love I could. I found it very hard.*

Things can seem so overwhelming, but be realistic about what to expect of yourself. You may need to rely on the help of others to get you through until you're feeling stronger.

You're only human. Give yourself permission to fall apart now and then. Take some time to talk to your family about how you're all feeling. Then you can pull yourself (and your family) together to do the things you need to do to support your child.

Take care of yourself

Remember, in order to take care of your child and your family, you need to take care of yourself. Children are very sensitive to their parents' mood and cope better when parents take care of themselves too.

- Make time for yourself. Try to do some of the things you did before your child got sick. Don't feel guilty that you need this time.
- Look after your health. Eat well, sleep well, deal with any of your own health problems, exercise when possible and take regular breaks from looking after your child.
- Talk to people – your spouse, partner, close friends and relatives or a counsellor – about your feelings, fears, concerns and hopes for your child.

- Turn to your child's healthcare team for support. Treatment centres have trained staff who can talk with you about your concerns. Some parents may take comfort in their religion or faith and may want to talk to the hospital's chaplain.
- Socialize. While you're feeling unhappy, it's tempting to avoid seeing friends and taking part in social activities. But do your best to keep up with your usual interests as much as possible and as your energy allows.



We didn't feel comfortable leaving our daughter when she was really sick. But friends would come over to socialize and visit with us – even for 20 minutes.

- Consider joining a support group. Treatment centres can provide names of support groups where you can meet with other parents of children who have cancer. Community resources can also provide support and information. They can tell you how other parents have dealt with the same types of situations you are facing.

Protect your relationship with your spouse or partner

Spouses or partners can support each other when a child has cancer. But sometimes the stress of caring for a sick child can cause friction in a relationship.

- Try not to bottle up your feelings. Parents often find it hard to express their grief and fears to each other. This can cause you to become tense and argue more than usual. If you can, try and talk to each other as openly as possible. A counsellor can help with the conversation if you find it hard to begin.
- Accept that everyone has different coping skills. This can reduce some of the tension between parents. Sometimes partners or spouses deal with the diagnosis in very different ways. One may find talking helpful, and the other may find talking too painful. There is no one right or wrong way to cope.

- Nurture and protect your relationship during this difficult time. Find private times to talk with your partner. Go on dates. Try not to talk only about your child with cancer.

“ *We felt guilty about spending time alone together, but friends cured us of that. They came by, said, “We’re here, and we’re babysitting. Now get out.”* ”

Single parents can feel even more overwhelmed by all the demands that come with a diagnosis of childhood cancer. As a single parent, you may need to rely on your network of family and friends even more than two-parent families. Let yourself do this.

Find easier ways to communicate information

It can be very stressful to keep everyone in your extended circle informed about your child’s condition. It’s up to you to decide what information to share and with whom. You can:

- Designate one family member or friend to receive new medical information to share with others.
- Gather together a group of people who are most supportive and involved to share new information, so you don’t need to repeat the same information over and over again.
- Tell family that you are simply too tired to talk, but that you appreciate the support they are giving.
- Leave a recorded message on your phone thanking callers and directing them to the family spokesperson.
- Send out a regular group e-mail, update a family web page or start a blog. To protect any personal family information you post on the Internet, you may want to set up some protections or controls on your website.

Let family and friends help you

Especially at the beginning, you may feel overwhelmed and confused by all the demands of having a child with cancer. Accepting help of all kinds – emotional, practical and financial – will help you get through this experience.

You're not alone if you find accepting help, let alone asking for it, really hard. This is understandable, but other parents who have been through what you're going through know from experience that people want to help, even if they don't know what to do.

“ *I had a hard time accepting help at the beginning, especially from my colleagues, or from a friend of mine who had a brand new baby. But it's important not to refuse help. You need it. I just told myself, at some point, in some way, I'm going to be able to help someone else. But right now it's my turn.*

“ *Accept help when it's offered. Having accepted help, you're then very quick to offer help in the future.*

“ *We had a lot of support we didn't realize, from our workplaces, from friends and family and our faith. Other people's faith as well: many people asked if they could pray for us at their churches, and that really felt good. When you have a child with cancer, you are embraced by the special system that never really goes away – the hospital, the cancer society and the wish foundations. If there is a relapse, you always know that the system is there.*

Choose a “point person”

You might find it helpful to choose a “point person” to organize things for you. The advantage of this is that it saves you time and energy, and you won’t need to directly ask a lot of people for help – but you’ll get the help you truly need.

Even if you’ve accepted the idea that you need help, you may not have the energy to figure out what you need, let alone find the time to phone many friends and ask. If you know what you need, a point person may be able to work from a list that you provide. Or the point person may know your family well enough to know what you need without being told. If you do feel awkward about asking for and accepting help, this set-up may really work for you.

To help you out, friends and family can:

- Shop for food that is easy to prepare, or already prepared. Limit perishables, since there may be times when you aren’t at home much.

“ *My office held a food drive for us. We ended up with an 8-month supply of meals in our freezer. It was enormously helpful to be able to just heat up dinner when we got home – and it saved a lot of money.* ”

- Prepare and deliver meals to the hospital or your home.

“ *I never would have known how much I appreciated having meals donated. Day after day after day you come home exhausted, and it was just so helpful to have a hot meal ready.* ”

- Feed and walk family pets.
- Take in the mail and look after the property.

- Do laundry, clean the house or water plants.
- Help look after siblings. They may need to be picked up from school, taken to after-school activities or driven to the hospital. They may need to go to another home when parents are not available. Siblings may also need emotional support and the comfort of having an adult who is there “just for them”.

“ *People helped out by driving our son to hockey and our neighbours told us they would babysit any time.* ”

- Give you some relief at the hospital. Visitors can bring a movie or game to the hospital and offer to sit with the child, so that the parents can take a break or share a meal together. Or visitors can sit and talk with you, to offer support, compassion and positive energy.
- Donate blood and platelets either for, or on behalf of, the child.
- Drop off magazines, newspapers or puzzle books to help pass the time.
- Give gift cards for the coffee shop in the hospital, gas, groceries or for long-distance calls. Even small change for vending machines is helpful.
- Give tickets to events and shows.

“ *Take advantage of offers of free tickets to sports, games, movies, aquariums, etc. If your child is too sick to go, siblings will appreciate them. Our son still maintains wonderful memories because of that one-on-one time.* ”

- Donate money or organize a benefit in the community on behalf of the child and family.

“ *People donated money, which came in handy because every day we had to pay for parking. And we didn't want to deny things to our family, like going on outings with the kids and visiting grandparents out of town.* ”

“ *My son's school raised money for us, but we felt like we couldn't take it. So we donated the funds raised to the hospital where my son was treated. That was when we thought that treatment would take only 6 to 8 months; in fact, we were in treatment for over a year. In hindsight, I wish we had taken the money. I would tell people to take all the help that they can get.* ”

- Find creative ways to help.

“ *A woman who collected coins at work and knew my daughter collected coins found special coins for her.* ”

“ *One person, an electrician, wanted to do something – anything – so he ended up doing a whole bunch of rewiring in our house. People try so hard.* ”

Keeping family together

When a child has cancer, a family's routines quickly disappear. Many families have said that keeping some routines going helped them cope during a difficult time. This was especially true for healthy siblings and for partners who couldn't spend as much time at the hospital as they would have liked because they had to keep working or caring for other children.

“We tried to keep as many of our family routines as possible: family movie night, eating dinner together, even having picnics in the hospital room.”

Helping siblings cope

When a child is in the hospital and is very ill, the focus is on that child. As a parent, you may not be able to pay as much attention to your other children. This may mean you miss their special school or sports events or you don't have the energy to play with them or help them with their homework.

As a result, being a brother or sister of a child with cancer can be very stressful. They may feel:

- worried about their brother or sister's health
- resentful, angry or left out because of all the attention that the child with cancer gets
- guilty that they are healthy, or about their negative feelings
- afraid they have caused the cancer
- isolated, as though no one understands what their life is like
- unimportant or "not good enough"
- sad or depressed

As a result of these feelings, you may notice behaviour changes. Siblings may start having physical symptoms like headaches or stomach aches. Problems in school are also possible. They may find it harder to focus with all the upheaval at home or because they have less help with homework. Their friendships can also suffer because their friends may not relate to what they're going through or because parents have less time to take them to their friends' houses for visits or activities.

Tips for helping siblings cope

- Talk to them about their feelings. Let them know it's okay to have strong feelings about cancer and how life has changed. Let them know that none of this is their fault.
- Talk to them about the cancer, the treatment and care. Siblings also need careful explanations about the diagnosis. They need to have at least as much information about the diagnosis and treatment plan as the brother or sister with cancer.

“ *A few months before he was diagnosed with cancer, my son had caught chicken pox from my daughter. When he was diagnosed, she thought she'd given him cancer as well. I never dreamed she would have thought that, and it really upset me. We had to explain things very carefully to her. I would tell parents to be honest and to give their kids as much information as they can handle, because they're thinking about it, even if they don't say much.* ”

- Prepare siblings for changes in your child's appearance. Cancer treatments can cause hair loss, weight gain or weight loss. These changes can be frightening for siblings.
- Involve siblings in your child's care. Let them come to appointments to see for themselves what the hospital, clinic and treatments are like. They can get to know the staff, ask questions, and spend time with their brother or sister playing games or watching TV or a movie together.
- Arrange to spend special time with siblings. This gives them an opportunity to have close times with you and may help them feel less resentful if they are getting less time and attention.

- Ask other family members and friends to spend time with the other children in the family. For example, an aunt or uncle might go to school events or attend important games or performances. A neighbour might help them with homework or take them on outings. This can be a good opportunity for siblings to form strong relationships with other important adults in their lives.
- Give them choices whenever possible. They might be able to choose where to go after school or who to spend time with when parents are at the hospital.
- Encourage them to take part in outside activities. Make a point of noticing and praising what they do in these activities.
- Talk to them about questions their schoolmates and friends may ask. Help them think of possible questions and answers so that they will feel comfortable talking about what's going on.
- Provide consistent discipline. Stick to the family's rules for behaviour for all children. Consistent discipline, while more difficult during these times, can help things feel as normal as possible for all children. Let siblings know that the child with cancer isn't being given special treatment. Let them know when they behave well and that you are proud of their accomplishments. Tell all your children how much you love them.
- Ask the healthcare team for help. Your hospital social worker, psychologist and child life specialist can help with sibling's issues. You may want to talk to the counsellor yourself, or set up an appointment for your child who is well. Counsellors may be able to recommend community or hospital programs especially for siblings of children with cancer.

Teachers can help siblings cope

To avoid worrying their parents, many brothers and sisters of children with cancer keep their feelings bottled up inside. These feelings may come out at school, where it is common for siblings to:

- withdraw and become very quiet
- become disruptive in the classroom
- cry easily
- become frustrated and have outbursts of anger
- fall behind in class work
- get lower marks than usual
- start missing school
- rebel against authority
- have arguments and fights with friends and other students in their class

Teachers need to know about the stresses facing your family and to understand that siblings' feelings may come out in the classroom. You can let your child's school and teachers know about the cancer diagnosis in the family, and ask for the school's help and support. Talk to the teachers about how they can help with the emotional and educational needs of all your children, not just the needs of your child with cancer.

When cancer is advanced

If your child's cancer hasn't responded to treatment, you will have different challenges in trying to help your child and family cope.

In children who have relapsed a number of times, parents and healthcare professionals must decide when it is time to end active treatment and focus on making the child as comfortable as possible. Some families need to feel they have tried every possible treatment option. Others find that a time comes when they feel they've done all that they can and do not want the child to suffer any more. There is no right or wrong time or way to make this very difficult decision.

You may want to think about where your child would be most comfortable - in the hospital, at home or in a hospice. Talk with your child's healthcare team about the different options available to you and your family. Talk with your child about what they want.

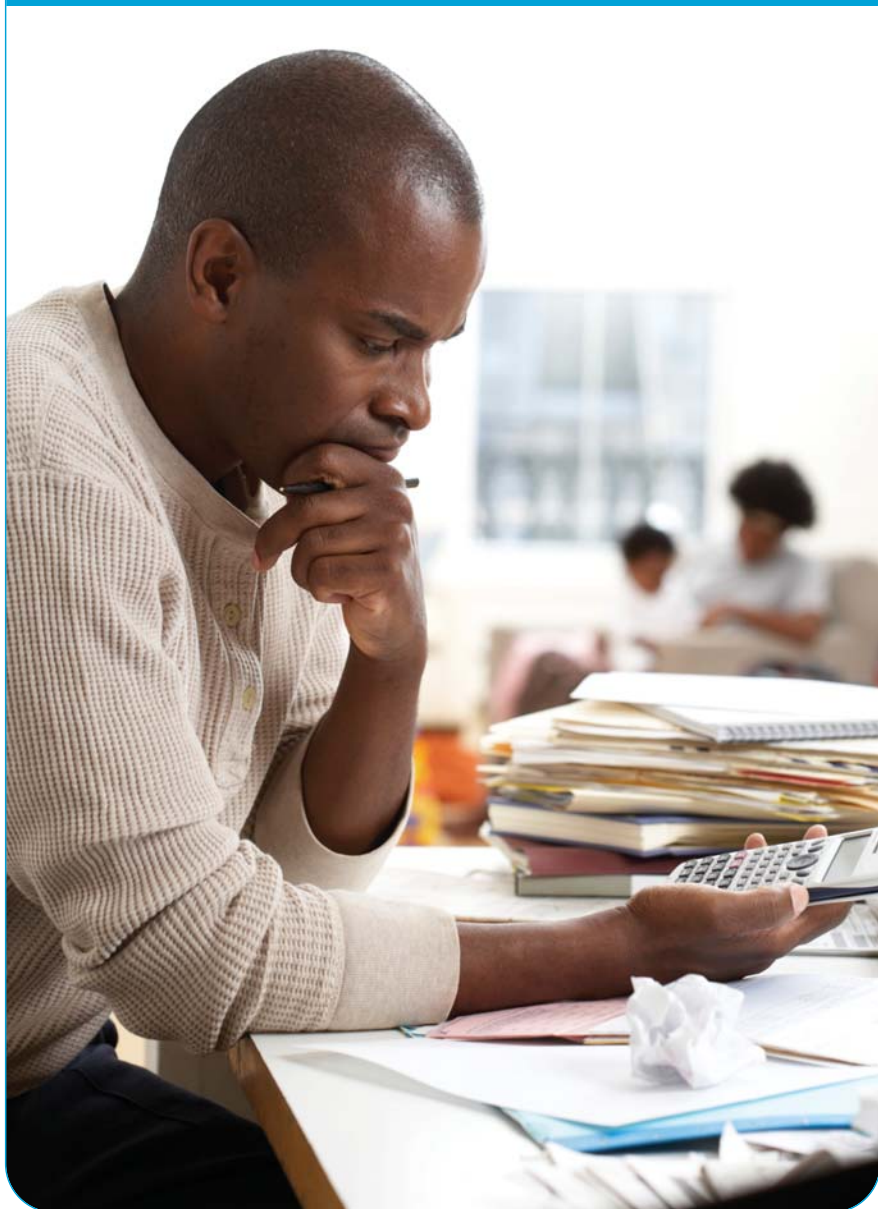
For more information about advanced cancer in children

Trained information specialists at our *Cancer Information Service* will take the time to answer your questions and search for the information you need on:

- symptom management
- nutrition
- emotional support for parents and siblings
- respite and palliative care
- end-of-life issues

Call us toll-free at 1 888 939-3333 (Monday to Friday, 9 a.m. to 6 p.m.) or e-mail us at info@cis.cancer.ca.

Dealing with Practical Issues



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This chapter offers suggestions about where to go for help to deal with the practical problems you may be faced with when your child has cancer:

- financial matters
- support services in your community

Financial matters

During your child's treatment you are focused mainly on their health, but you may have some concerns that relate to financial matters. You may worry about how you might support yourself and your family if you aren't able to work for any length of time while you care for your child. And you might have to spend more money on medicines or therapies not covered by provincial or private health insurance plans.

Talk to a social worker at your child's cancer centre if your income has been affected by cancer. There may be some programs that help by reimbursing families for some of the costs they incur during their child's treatment. You'll probably want to find out about financial assistance programs and government benefits.

For information on government services

For information on government services and how to apply for them, contact your local Human Resources and Social Development Canada office at 1 800 0-Canada (1 800 622-6232) or visit www.servicecanada.gc.ca. You may be eligible for Employment Insurance (EI) Compassionate Care Benefits.

Your workplace may offer financial or other support, such as paid or unpaid leave to care for your child. Ask your human resources department about what support is available.

Account managers at your bank, financial planners or advisors can also help with budgeting money. They can offer advice about whether to use equity from your home, RRSPs or other investments. The Financial Planners Standards Council (FPSC) has helpful information on finding a certified financial planner.

Support services in your community

Depending on where you live, you may be able to access a variety of services, including transportation to treatment, accommodation near the hospital, respite care and camps for children with cancer and their families.

To find out what's offered in your area, you can search our Community Services Directory on www.cancer.ca, or call one of our information specialists at 1 888 939-3333 for help. Our directory lists cancer-related services offered by the Canadian Cancer Society and other organizations. We can help you find one that suits your needs.



After Cancer Treatment



Photographed by Mike Pochwat ©, PhotoSensitive

After a long cancer journey, you and your family have now reached the “after treatment” stage. Once treatment is finished, the focus shifts to:

- follow-up care
- adjusting to the new “normal”
- possible late effects of childhood cancer
- moving toward the future

Follow-up care

After cancer treatment, the goal is to help your child stay as healthy as possible – to stay well and to do well in school, socially and, later, at work.

Your child’s cancer treatment summary

When your child finishes cancer treatment, most treatment centres provide a record of the cancer treatment received. This record is a very important document. It will help healthcare professionals give your child the best possible care in the future. Keep a copy of the cancer treatment summary in a safe place, and give a copy to each of your child’s healthcare providers.

Getting the most out of follow-up care

Children who have been treated for cancer will continue to have regular checkups after treatment has ended. Care is often shared between family doctors or pediatricians and cancer specialists. At these checkups, your child receives both the healthcare needed by any child that age and special care based on the type of cancer and treatments they had. Your child’s doctors will guide you in what to expect.

To make sure that your child gets the most out of follow-up care:

- Keep up with appointments. Your child's doctor will let you know how often your child should be seen and whether to see a cancer specialist regularly. Every child's schedule will be different.
- Be alert to signs of the possible return of cancer. Doctors have no way to tell for sure whether cancer will return. Talk to your child's healthcare team about the chances and signs of cancer returning.
- Be alert to signs of late effects of cancer treatment. Cancer treatment may cause side effects many years later.
- Watch for any problems your child may have in dealing with having had cancer. Once all the activity of treatment is over, some children suddenly fully realize what happened to them, even years after treatment has ended. This can be very upsetting. At this point, they may need to talk about their feelings. It may help to see a counsellor.
- Promote healthy habits. Eating well and getting enough sleep and exercise will help your child heal, feel better and be healthy.
- Discourage smoking. Smoking increases the risk of cancer developing.

Adjusting to the new “normal”

Finishing treatment can be a time of great happiness and relief. Some families find that having a celebration of some sort helps signal a new phase in family life. Especially for younger children who may have spent much of their lives taking pills and having tests, ceremonies can help them to understand that treatment is truly over.

To celebrate the end of treatment, you might:

- Take “good-bye” pictures of the hospital and staff.
- Give trophies to your child and their siblings for all that they have achieved.
- Ask the clinic to present your child with a certificate for completing treatment.
- Have friends and family send congratulations cards to your child.
- Go on a family vacation or set aside some special family time.

This can also be a time of confusion and mixed feelings. You may feel at a loss without the schedule of treatments, or lonely without the constant support of the healthcare team. You may worry about cancer coming back in the future, or have some concerns about adjusting back into “normal” life. You may be overwhelmed by the demands for monitoring and follow-up care for your child. You’re not alone if you feel this way.

“ *Brace yourself for the end of treatment. The strings are cut and you’re on your own. When you’re in treatment, all you think about is treatment – and when you’re done, you suddenly feel cut off from everything.* ”



At the end of treatment, you're all finished, you get this little trophy or certificate, and you're suddenly let go. It's the end. That's the hardest part. Now what? Will the next MRI be clear? What side effects will show up? You have to get used to the new "normal".

Getting back to "normal" could mean:

- deciding when and how quickly to return to work for parents and to school for children
- finding a balance between risk and caution as your child returns to everyday activities – the healthcare team can tell you what is risky, and they can help you learn to gradually “let go” of protecting and controlling every part of your child’s life and decisions
- changing roles and schedules of family members as you spend less time at the hospital or clinic
- rediscovering that old “problems” that existed before the cancer still need attention
- changes in relationships with the pediatric oncology team
- changes in relationships with family and friends

If you have mixed feelings at the end of therapy, it can help to schedule a final visit with members of your child’s healthcare team to ease the transition. You can ask questions and get some guidance about the years to come.

Going back to school

If your child has missed a lot of school, going back when treatment is over can be either a relief or a challenge. Readjusting to school life may be something you've already been through a couple of times during treatment, or this may be the first time you're dealing with these issues.

Many children look forward to returning to school and their friends – it's a big sign that life is returning to normal. Other children may worry – for example, about having missed too much school and never being able to catch up to where friends are.

Some children and especially teenagers may dread returning to school because their appearance has changed. They may be afraid of the reactions of others if they're missing a limb or if their hair is still growing back. They may also worry that being away may have changed their relationship with their friends or affected their standing within their group.

These tips may help ease your child's transition back to school:

- Ask a nurse or social worker to talk to your child's class about what has happened, and how your child will look and feel when returning to school. This could include a question-and-answer session to clear up misunderstandings and reassure the students.
- Involve an older child or teenager in deciding what information should be given to classmates.
- Ask about back-to-school programs at your cancer centre, which may help children and classmates understand the diagnosis and know what to expect.
- Invite one or two classmates over to get reacquainted with your child before school starts (especially if your child has had to be out of touch with friends). Young children may treat returning children almost as strangers. If your child knows a friendly and welcoming face will be in the schoolyard, it may help.

- Keep teachers informed. Teachers play an important role in easing your child's transition to school. Let the school and teachers know if your child is emotionally or physically fragile.

“ *My daughter's legs got really weak, and she had to take the elevator at school, which she hated, because she didn't want to be different. Her teacher was really good about it. She let groups of kids take the elevator so that my daughter didn't stand out.* ”

School performance

Cancer treatment can affect a child's ability to learn. Learning difficulties can be very frustrating and may affect your child's confidence and self-esteem. Your child's school may give extra help for learning difficulties. If you think your child may have problems, talk to their teachers about the help that they can give.

If your child finds the return to school very difficult, you can talk to the school or a social worker about other education programs.

“ *My son found returning to school very difficult. He had learning difficulties after treatment for a brain tumour. After missing 14 months of school, he also missed the transition to high school with his peer group. Every day he met with how different he was – from his peers and from before. He and I made the decision to home-school with the support of an outreach program. The whole goal is to give him the feeling of success and to feel good about himself. He absolutely prefers it.* ”

Possible late effects of childhood cancer

Some children may have long-term health problems, or “late effects,” from their cancer treatment as they grow into teenagers or adults. Some of the most common late effects of cancer treatments are included below.

Heart and lungs

Some chemotherapy drugs and radiation therapy to the chest can have long-term effects on the heart and lungs. This is most likely to happen in children who received higher doses of these therapies, and in those who received their treatment before their heart finished growing.

Children who are at risk for heart and lung problems will be followed up regularly with echocardiograms, lung function tests or both. Your child may see a heart or a lung specialist if the tests show any sign of these problems.

Puberty and fertility

Some types of chemotherapy, and radiation to the brain and pelvis, may delay puberty and affect fertility (the ability to have children). Total body irradiation, usually done with a bone marrow or stem cell transplant, can also affect puberty and fertility. Girls may also be at risk for early menopause in the future.

Depending on their age, children may be monitored carefully at follow-up appointments for signs of puberty, and later, for fertility. If puberty appears to be delayed, hormone replacement therapy may be needed. If fertility is likely to be a problem, older boys may be given the option of sperm banking before starting treatment.

Most survivors of childhood cancer go on to have children if they choose, but some may not be able to. It can be very distressing to think that your child may not be able to have children in the future. Your child may also find this difficult to cope with, either now or when moving toward adulthood. Members of your child's healthcare team are there to help with any concerns you have.

Thyroid

Head or neck radiation can sometimes cause the thyroid gland to stop working properly. This gland helps regulate growth, weight and the balance of body chemicals. Blood tests can be done to check thyroid hormone levels. Low thyroid levels are easily treated with thyroid hormone pills (*hormone replacement therapy*).

Growth and development

Radiation therapy, especially radiation to the brain or spine, can sometimes slow or stunt a child's growth and development. At follow-up appointments, your child will be weighed and measured. If growth has been affected, tests will be done to see if growth hormone replacement is needed.

Kidney problems

Certain chemotherapy drugs can cause problems for the kidneys. Fortunately, these problems usually aren't severe. If your child has had these drugs, the kidneys should be checked regularly. Children whose kidneys are working well at the end of treatment will not likely have kidney problems in the future. Removal of one kidney as part of treatment does not usually cause any problems because the remaining kidney can make up for the one removed.

Intellectual development and education

Most children who have been treated for cancer are able to continue on with their education, and their intellectual development is not affected. But some – especially those who have been treated for brain tumours – may develop learning difficulties. They may need special help at school. The extent of these learning difficulties will depend on the child's age and the type of treatment they had.

If your child needs special help with school as a result of cancer treatment, your doctor, psychiatrist, psychologist and social worker can help provide details of treatment, assess your child and let you know about any assistance or government programs that are available.

Second cancer

A very small number of children who are cured of childhood cancer can get a different cancer later on in life. There are two main reasons for this. Some chemotherapy drugs and radiation can increase the risk of a second (different) cancer, while some children may be at risk for a second cancer because of genetic disorders or syndromes.

Talk to your child's doctor about the best ways to monitor your child's health in the future.

Moving toward the future

Your family has been through a lot. Try to be kind to yourselves as you adjust and begin to look to the future. Being treated for cancer at a young age is always a difficult experience. Being the parent of a child of cancer is also very challenging.

Having survived that experience, you and your child have learned many things. Most likely, you are both stronger than you were before the diagnosis.

“ *My son is a different person. He’s more emotional, more empathetic. He won’t put up with anyone bullying or teasing his friends. He is generally more aware of life around him because he’s come face-to-face with death.* ”

As you and your family move forward into the future, use those strengths to your advantage. While it’s hard to imagine anything positive about your child having had cancer, you may be surprised to find that your family has gained from the experience. Families of children with cancer often have an increased knowledge of disease, increased empathy for the sick or less able, increased sense of responsibility and confidence to “speak up” for themselves, enhanced self-esteem, greater maturity and coping ability and increased family closeness.

“ *Life has changed. Now, every day is important. We don’t necessarily need to clean up the dinner dishes right after dinner like I always did before. We’re going to play with the kids, go swimming, whatever. After they go to bed, then I can do the dishes. But I’m not going to let a day go by that isn’t fun in some way, that isn’t a happy time.* ”



Resources



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Canadian Cancer Society

Helping you understand childhood cancer

You may want to learn more about your child's cancer. Trained information specialists at our *Cancer Information Service* take the time to answer your questions over the telephone and search for the information you need about:

- diagnosis and treatment options
- managing side effects during treatment
- nutrition
- emotional support for parents and siblings
- long-term effects after treatment
- respite and palliative care

You may also find our booklet *When Your Child Has Cancer: A guide to good nutrition* useful.

Talking with someone who has been there

If you would like to talk to someone who has cared for a child with cancer, we can help you connect with a trained volunteer.

To contact the Canadian Cancer Society:

- Call us toll-free at **1 888 939-3333**
Monday to Friday, 9 a.m. to 6 p.m.
- E-mail us at info@cis.cancer.ca.
- Visit our website at www.cancer.ca.
- Contact your local Canadian Cancer Society office.

Our services are free and confidential.



Suggested websites

For parents and families

Childhood Cancer Foundation Candlelighters Canada

www.candlelighters.ca

Leucan Information Centre

www.centreinfo.leucan.qc.ca/en/

CureSearch

www.curesearch.org

National Cancer Institute – Childhood cancers

www.cancer.gov/cancertopics/types/childhoodcancers

St. Jude Children’s Research Hospital

www.stjude.org

Macmillan Cancer Support

www.cancerbackup.org.uk/Cancertype/Childrenscancers

For children and teens

Re-mission

www.re-mission.net

A game and community for teenagers and young adults living with cancer.

Captain Chemo

www.royalmarsden.org.uk/captchemo/

Provides information on treatment, side effects and medical tests. The interactive Captain Chemo games help children deal with their cancer.

TIC – Teen Info on Cancer

www.click4tic.org.uk

Presents cancer information, advice and support for teens on how to cope with cancer. Includes an online space to share experiences.

Canadian Cancer Society Division Offices

British Columbia and Yukon

565 West 10th Avenue
Vancouver, BC V5Z 4J4
(604) 872-4400
1 800 663-2524
inquiries@bc.cancer.ca

Alberta/N.W.T.

325 Manning Road NE
Suite 200
Calgary, AB T2E 2P5
(403) 205-3966
info@cancer.ab.ca

Saskatchewan

1910 McIntyre Street
Regina, SK S4P 2R3
(306) 790-5822
ccssk@sk.cancer.ca

Manitoba

193 Sherbrook Street
Winnipeg, MB R3C 2B7
(204) 774-7483
info@mb.cancer.ca

Ontario

55 St. Clair Avenue W
Suite 500
Toronto, ON M4V 2Y7
(416) 488-5400

Quebec

5151 de l'Assomption Blvd.
Montreal, QC H1T 4A9
(514) 255-5151
info@sic.cancer.ca

New Brunswick

PO Box 2089
133 Prince William Street
Saint John, NB E2L 3T5
(506) 634-6272
ccsnb@nb.cancer.ca

Nova Scotia

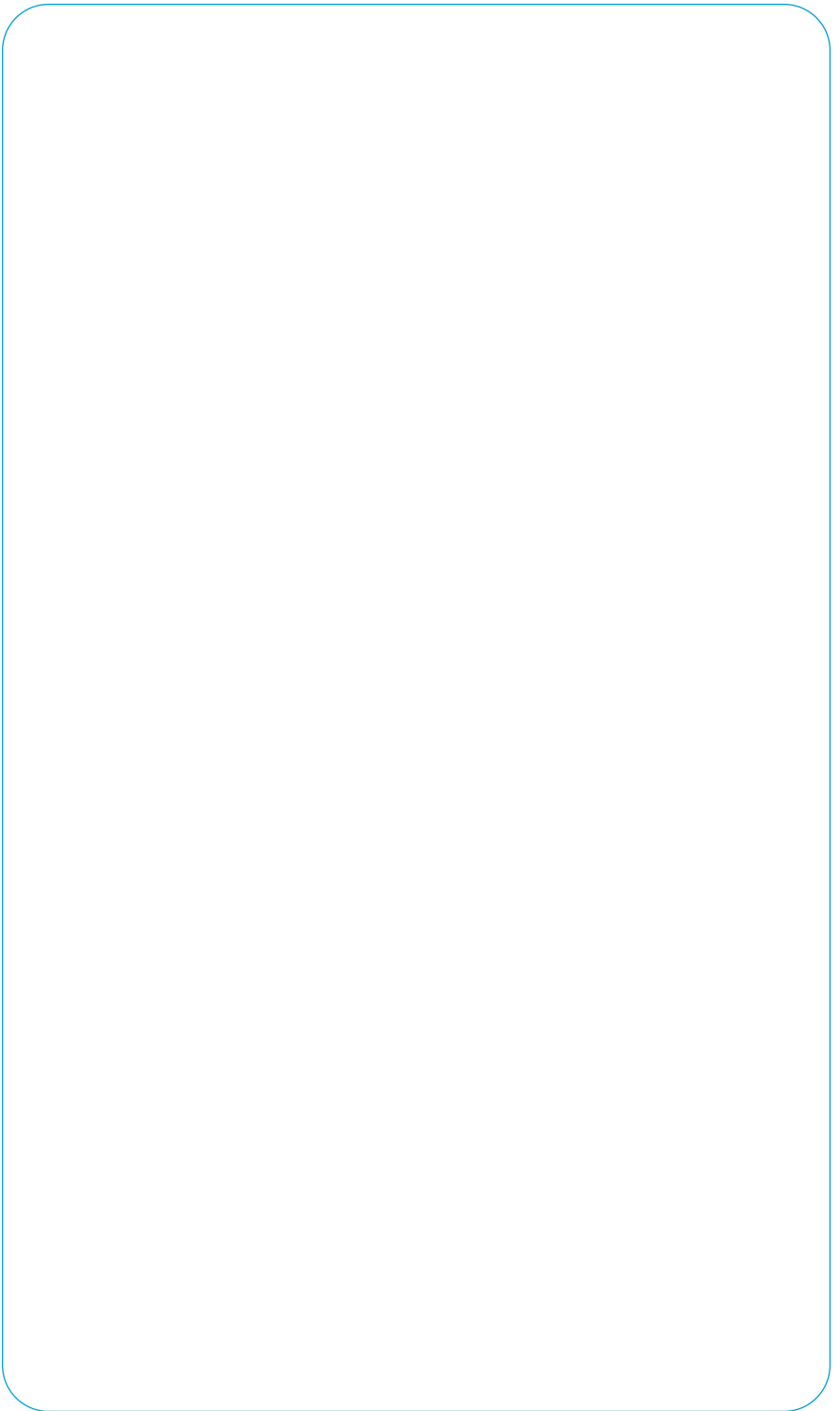
5826 South Street, Suite 1
Halifax, NS B3H 1S6
(902) 423-6183
ccs.ns@ns.cancer.ca

Prince Edward Island

1 Rochford Street, Suite 1
Charlottetown, PE C1A 9L2
(902) 566-4007
info@pei.cancer.ca

Newfoundland and Labrador

PO Box 8921
Viking Building
St. John's, NL A1B 3R9
(709) 753-6520
ccs@nl.cancer.ca



What we do

Thanks to the work of our volunteers and staff, and the generosity of our donors, the Canadian Cancer Society is leading the way in the fight against cancer. The Canadian Cancer Society:

- funds excellent research for all types of cancer
- advocates for healthy public policy
- promotes healthy lifestyles to help reduce cancer risk
- provides information about cancer
- supports people living with cancer

Contact us for up-to-date information about cancer, our services, or to make a donation.



Canadian Cancer Society
Société canadienne du cancer

Let's Make Cancer History
1 888 939-3333 | www.cancer.ca

This is general information developed by the Canadian Cancer Society.
It is not intended to replace the advice of a qualified healthcare provider.

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