



Canadian  
Cancer  
Society

# When Your Child Has Cancer



1 888 939-3333 | [cancer.ca](http://cancer.ca)

We would like to thank the people who shared their personal experiences with us. To protect their privacy, and with their permission, we have changed their names.

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## Introduction

Having a child with cancer is one of the biggest challenges a parent can face. There is some good news, and that is that new and better treatments help many children with cancer. Every case is different, but more children survive cancer now than ever before.

Before writing this booklet, we talked to parents of children with cancer to find out what their needs were. We weren't surprised to hear that they had very good medical information from their healthcare team. But what parents often didn't have - and what they really needed - was a different type of information. They needed information that would help the whole family manage and cope with their cancer experience. This booklet can help.

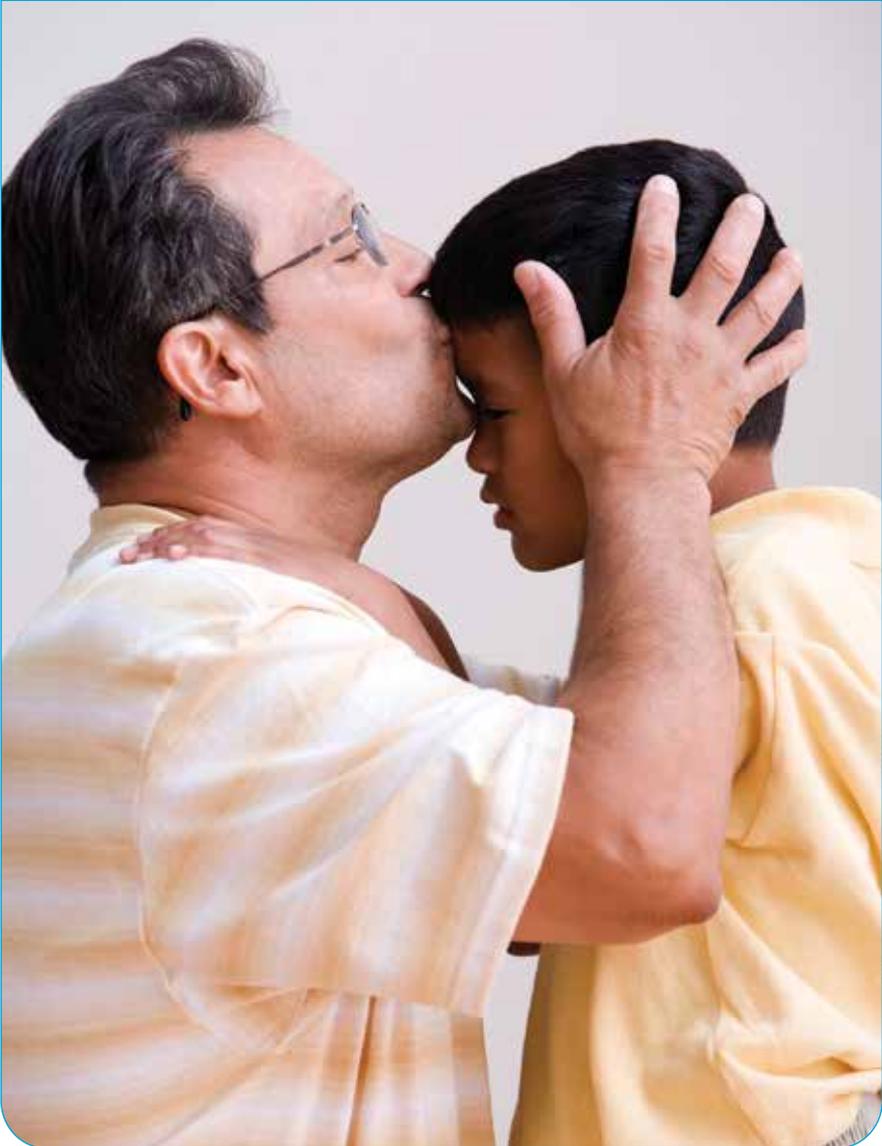


Parents told us that they still want a printed booklet and they will go online for information that adds to what is in print. And so you'll see suggestions to visit [cancer.ca/whenyourchildhascancer](http://cancer.ca/whenyourchildhascancer) for more information.

Throughout the booklet, you'll hear stories from parents who've been where you are now. Their stories may not be the same as yours but are offered here to help you understand that you're not alone and that you can work with your healthcare team to get the care and support you need.

This booklet has been written for the parents and caregivers of children with cancer, but other members of your family or close friends may also find it helpful. It will help them understand what you're going through on the journey to cure your child's cancer. And that, in turn, will make them a better source of support for you and your family.

# Your child has cancer





‘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.

When a child is diagnosed with cancer, families can feel overwhelmed. Hospitals, doctors, treatment plans – there is so much to learn and many decisions to make. You don’t have to go through it alone.

## What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of trillions of cells grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell tell it to grow, work, divide and die. Normally, our cells follow these instructions and we remain healthy.

But sometimes the instructions in some cells get mixed up and the cells don’t behave the way they should. These abnormal cells start to grow and divide out of control and crowd out normal cells. After a while, a group of abnormal cells sometimes forms a lump (called a tumour).

Tumours can be either non-cancerous (benign) or cancerous (malignant). Non-cancerous tumour cells stay in one place in the body and are not usually life-threatening. Cancerous tumour cells can grow into nearby tissues and spread to other parts of the body. It’s important to find and treat cancerous tumours as early as possible. In most cases, finding cancer early increases the chances of successful treatment.

Cancer cells that spread to other parts of the body are called metastases.

Most cancers are named after the part of the body where they start. For example, cancer that starts in the bone but spreads to the lung is called bone cancer with lung metastases.

Blood cancers are a little different than cancers that form solid tumours. Abnormal blood cells crowd out normal blood cells in the blood, bone marrow or lymphatic system. Blood cancers are named after the type of blood cell that is abnormal.



**Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) for in-depth information about different types of childhood cancer.

## The healthcare team

Children's cancer treatment takes place in treatment centres or units in hospitals that specialize in diagnosing and treating babies, children and teenagers who have cancer. These centres are staffed by many different healthcare professionals who can help your child and your family in different ways. These skilled people work together to make sure your child gets the best treatment available with as few side effects as possible.

“ 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 members of healthcare teams may be different, depending on where you live and on the centre where your child is treated. Some of the people you will meet are listed below. If you do not meet one of these people but you think they might be able to help you, ask someone on your team about a referral.

“ 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 specialities, 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. ”

### The Children's Oncology Group

Pediatric oncologists at most Canadian hospitals are part of an international research group called the Children's Oncology Group (COG). Through COG, oncologists receive information about new and improved treatment plans as soon as the information is available.

An **art therapist** helps your child express and understand their emotions through art and the creative process.

A **child life specialist** is trained in child development and understands how children react to illness and being in the hospital. They use activities that are based on child's play to help children understand their diagnosis and cope with tests, procedures and treatment. Child life specialists can help you understand your child's behaviour and offer suggestions to help you support your child and your child's siblings.



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 registered **dietitian** teaches you about healthy eating and helps with problems your child may have with food while being treated.

**Doctors**, or **physicians**, have different roles and responsibilities in cancer care. You will meet many different types of doctors during your child's treatment, including:

- An **anesthesiologist** or **anesthetist** gives drugs that cause a loss of feeling or awareness (called anesthetics) to prevent or relieve pain during surgery and other procedures done in the hospital.
- An **orthopedic surgeon** is a doctor who specializes in diseases and injuries of the bones.
- A **pathologist** looks at tissue samples taken from the body to diagnose illness or see how the cancer is responding to the treatment.
- A **pediatric hematologist** specializes in diseases of the blood and blood tissue in children.

- A **pediatric oncologist** specializes in planning and giving cancer treatment to children. A pediatric oncologist is usually the main doctor for your child.
- A **surgeon** is a doctor who performs biopsies or surgeries. A **pediatric surgeon** is a doctor who specializes in surgery in children.
- A **surgical oncologist** is a doctor who specializes in performing biopsies and surgeries or other procedures involved in diagnosing or treating cancer.

Many children's cancer centres are in teaching hospitals, which means they are connected to a medical school. In a teaching hospital you will meet doctors who have different titles and different levels of responsibility. **Resident** and **fellow** are titles you might hear for doctors who are taking more specialty training.

Before being diagnosed with cancer, your child probably went to a **family doctor**, or **general practitioner (GP)**, for their healthcare needs. Some children have a **pediatrician**, which is a doctor who cares for babies, children and teens. The healthcare team will update this doctor with information about your child's cancer and treatment. Your child may see this doctor for checkups during treatment.

A **music therapist** uses music to help your child cope and provide emotional support. Activities may include singing, writing songs, playing instruments, telling stories through song and listening.

A **neuropsychologist** is a psychologist who specializes in understanding the relationship between the brain and behaviour. They assess certain skills and functions in children, such as attention, memory, language, fine motor skills, academic skills and problem solving. Neuropsychologists can help children who have learning problems as a result of cancer and its treatment.

**Nurses** give daily nursing care for your child in the hospital, in a clinic or at home. They often have the most contact with your child and will answer questions, give medicines and provide emotional support. Many nurses will care for your child, and there are different types of nurses with different specialties. An oncology nurse is trained to care 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 **pain specialist** treats pain. Pain specialists include anesthetists, neurologists, palliative care doctors and nurses, pharmacists and psychologists.

**Palliative care team** members focus on providing relief from the symptoms and stress of cancer and on improving the quality of life for the whole family. Palliative care can be given at any age and at any time after a cancer diagnosis. It can be given along with treatments to cure cancer. Palliative care is provided by different healthcare professionals including doctors, nurses, psychologists, social workers and child life specialists. This team works with your child’s oncologist and treatment team to manage your child’s comfort.

## Parents and caregivers

You can help your child by being involved in their cancer care. The healthcare professionals on your team are experts in diagnosing and treating cancer and managing side effects – but they don't know your child like you do. You can:

- Learn about your child's condition, treatment and side effects.
- Share information about your child's medical history, current medicines and supplements.
- Keep track of your child's medicines, test results and papers.
- Tell the team how your child reacts to treatment, what your child needs and how they feel.
- Tell the team about your child's cultural customs, preferences and religious beliefs.
- Help your child cope with tests and procedures.
- Help give medicines to your child.
- Speak out if you feel uncomfortable or need support.

Be honest about how much you are able to do to care for your child. It's normal to be uncomfortable with the idea of giving medicines or taking part in caring for a very ill child. On some days, you may be too exhausted to do things that you have been doing regularly for days or weeks. That's why it is very important to talk with your team about finding other ways to manage.

*"There were times when we'd have to hold my daughter down to take medicine. There were a couple of times where I had to leave the room. I went, you know what, do what you have to do. I'm going out in the hallway, turning my head. I don't want to know how you guys do it. I don't want to see it."*

A **pharmacist** prepares drugs and other medicines and explains how they work. An **oncology pharmacist** specializes in chemotherapy and other cancer drugs. They will tell you about side effects and how to deal with them.

A **physiotherapist** or **occupational therapist** works with your child to restore or maintain physical fitness. They can help if your child has a hard time moving around or doing daily activities.

**Psychiatrists** and **psychologists** are mental health specialists. They can help your child and your family understand and cope with feelings, thoughts, worries and behaviours. They may also test your child to see whether the cancer treatment is affecting their learning.

“ 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 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 help.

**Radiation therapy team** members work together to provide radiation therapy to your child.

- A **radiation oncologist** is a doctor who specializes in treating cancer with radiation. They develop the treatment plan for your child.
- A **radiation therapy nurse** provides nursing care during radiation therapy. They talk to you and your child about treatment and help you manage your child’s side effects.
- A **radiologist** is a doctor who reads and interprets x-rays, ultrasounds, CT scans, MRIs and other scans.
- A **radiation therapist** helps plan and deliver treatment and will help manage your child’s side effects.

A **social worker** helps you and your family cope with the illness and its treatment. Social workers can provide counselling or refer you to counsellors, support groups, financial help and other resources.

“ I had a very good social worker. Anything I found out about, she found out more. I had a bill from Bell Canada for \$800 on my cellphone for all my calls. Bell Canada forgave it. It was things like that that were so amazing. She wrote the letter and she would find supporting documents.

“ I needed help with everything and was very thankful for being assigned a social worker at the hospital who held my hand through it all. I didn't know what to do, where to live, where to eat. I didn't know the first thing about looking after a sick child or really anything about chemotherapy.

A **spiritual care worker** is trained to offer support and prayer according to your family's spiritual and religious needs.



#### **Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) to learn more about the healthcare team and how to work with them.

## Your child's treatment plan

After your child is diagnosed, the healthcare team will develop a treatment plan, or protocol, that is designed just for your child. Children with the same cancer can have very different treatment plans. A treatment plan outlines the types of treatments, how they are given and about how long the treatment is expected to last. These plans may also change over time, depending on how treatment is working.

“ 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 7 months, but it lasted over a year. For example, his red and white blood cells had to be at certain levels for the 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.

Your healthcare team will talk to you about:

- the type of treatment they think your child needs and how long it may take
- the advantages and disadvantages of the treatment and how well it usually works
- other types of treatment to think about, including clinical trials
- risks or side effects of the treatment

“ Write down questions when you're going in so you don't forget. That's a big thing. And if they don't answer it with something you can understand, ask again. Just keep on asking until you get an answer you can understand.

If you have any questions or don't understand something, ask about it. Many people need to hear explanations about cancer treatment a few times before they really understand them.



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.

### **Palliative care**

If you're offered palliative care for your child and family, don't panic. Many people think palliative care is only offered when death is near, but palliative care can be given along with treatment to cure your child's cancer. This type of care relieves symptoms of cancer or its treatments. Think of it as an extra layer of support. Palliative care can help everyone in the family cope with the stress of treatment and have a better quality of life from the time of diagnosis onward.

### ***Giving consent***

Before your child has any treatment, or if their treatment gets changed, the doctors will meet with you to explain the treatment plan and treatment goals. At that time, they will ask you to decide whether you will let your child have the treatment they recommend. This is called giving consent.

In some provinces, your child may be old enough to give consent. Assent is used when a child is not old enough to give consent but can understand that they have cancer and need treatment.

## *Clinical trials*

Someone on your healthcare team may ask you if you would like your child to be part of a clinical trial. They are a common part of childhood cancer treatment.

Clinical trials compare standard treatments, which are the treatments being used right now, with newer ones. The new treatments are often very similar to the standard treatments but with some changes. Researchers study the changes to see if the new treatment will cure the disease in more children, control the disease longer or cause fewer side effects.

When there is clear evidence that the tested treatment does work, trials can be stopped early – and then every effort is made to offer everyone in the trial the new treatment.

### **It's your choice**

Clinical trials are carefully designed to have as few risks and as many benefits as possible for everyone who takes part. Your healthcare team will go over the benefits and risks with you and your child.

For a child to take part in a clinical trial, parents need to give permission. It's up to you and your child, not anyone on the healthcare team. The trial must be explained to your child in a language they can understand or by using visual aids. Your child will then be asked for their agreement to take part.

If you decide not to take part in a clinical trial, or if you remove your child from a trial, your child will continue to receive the best known treatment available. Your choice will not affect how the healthcare team cares for your child.

## Where to go for information

Terry's daughter, Isabella, was diagnosed with acute myelogenous leukemia when she was less than a year old. The diagnosis was very sudden, and like most parents, Terry knew nothing about the disease. The next day, he turned to the Internet for information. His biggest piece of advice for parents is to wait until you've heard from the doctor before you start researching. What he found online scared him so much that "I closed my computer and from that point on I never looked at the Internet for information regarding leukemia. I depended upon the doctors. For me, the Internet was not my friend."

There's a lot of information out there about cancer. It's in books, online, in magazines and in newspapers – and in your social media newsfeeds. Some of it is accurate, and some of it isn't. And even if the information is correct, that doesn't mean it applies to your situation or your child. Talk about information that you find with your child's healthcare team – they welcome families to bring in information and go over it together.



I would caution parents not to use the Internet to look up every single thing ... there's so much information out there and not all of it is as it sounds. When you do it too much, you come to expect the worst instead of the best.

### **The Canadian Cancer Society as a source for information**

The Canadian Cancer Society offers you information in print, online at [cancer.ca](http://cancer.ca) and by phone at 1-888-939-3333. This information can help you, but it is never meant to replace your relationship with your doctor or another healthcare expert on your team.

Our information is updated regularly and it's reviewed by Canadian experts before we share it with you. But only your doctor can tell you whether it's right for your child and your situation.

Some hospitals give parents a binder of information about cancer and the hospital. If you aren't given anything, ask your healthcare team if they have brochures or books you can read or if they can suggest trustworthy websites to check for information.

“ One of her doctors runs a not-for-profit website to do with her kind of cancer. They're very informational in a non-scary way. They tell you what to expect and normal things - not necessarily pleasant things - but normal things to expect. That's where I've got most of my information. I'm also a reader. The hospital offers reading material on different things. In regards to her cancer, they give you a binder when you're first diagnosed so that you can read through the information.

Online support groups, mailing lists and chat rooms can be helpful because they connect you with other parents in similar situations and you can share information. Be sure to check with your healthcare team about this information, too.

“ I belong to a couple of support groups and it's pretty much just parents ... I find that helps. Especially when you're thrown into a new situation or something new they want to do. There are people available to ask - What was your experience with this? Is there anything I should know about? Anything I should ask?

### **Joanne's story - The power of information**

Joanne and her partner knew a lot about cancer before their daughter, Abigail, was born. Abigail's dad had retinoblastoma, a cancer that starts in the membrane at the back of the eye, when he was a child. There was a chance their baby would be born with it, so Joanne learned what she could about it. She then arranged for an eye specialist to check Abigail right away. The on-call pediatrician thought they would be wasting the specialist's time, but Joanne insisted. "I said, you're entitled to your opinion but she's still getting checked." The specialist found tumours in both eyes within minutes.

While Abby was being treated, Joanne read everything she could - binders of information from the hospital, books and online information recommended by Abby's doctor. She joined an online group for retinoblastoma. "The similar experience helps. Especially when you're thrown into a new situation. You can

ask other parents, What was your experience with this? Is there anything I should know about? Anything I should ask? When you're in that moment in the doctor's office or in the hospital, sometimes you just go blank. You don't ask what you want to ask."

With Abby going through treatment far from home, her big brother, Alexander, who was 3 when she was born, had a very rough time. He was often angry with Abby and had a hard time getting along with his peers. Joanne and her partner again turned to expert information and education to help. They took a parenting course to learn different ways of dealing with Alexander's behaviour. "It seemed to help. It also seemed to keep us in a more calm state of mind when we're dealing with him. We're learning that if we don't escalate, he tends to calm down a lot easier."

Life went on – and Abby's treatment was successful. She grew into a happy, easygoing 3-year-old who smiles at the nurses when they're about to prick her finger for a blood test. But Joanne knew a lot about this disease and the high risk that it would come back. Abby relapsed with a new tumour a year and a half after finishing treatment. This time, the healthcare team recommended a stem cell transplant but Joanne and her partner weren't sure. "We very much questioned the stem cell transplant. We were thinking if the cancer is contained in the eye, why does she have to go through the transplant and the chemo and possible radiation if it's contained?" They needed more information.

Joanne and her partner met with the transplant doctor, the fellow and the nurse coordinator. "They were very, very helpful. They kept asking if we had any questions, if there was anything we didn't understand." The team gave them a book written by a transplant survivor. "It was absolutely amazing because you're reading from somebody who has gone through it, not just somebody who is telling you about it. It helps you to understand more."

After several more meetings with the oncologist they understood that the new tumour wasn't only in her eye. "Once we understood that it was actually contained in other tissue, we were more comfortable going through with the transplant. We still don't like the idea but with more information we understand it could save her life. And we want her to live."

## **Keep helping your child to learn and grow**

Cancer treatment can last for many weeks or up to several years. There will be times when your child feels too sick or too uncomfortable to do some of the things they did before they got sick. But there are many things you can do to help your child continue to learn and grow and enjoy life during treatment.

### ***Set clear expectations about behaviour***

Even when sick, children need consistency, structure and guidance from adults who are in charge. Sometimes parents let their children behave differently when they are sick because they feel sorry for them. But if you take it too far, this change sends a message that children can do whatever they want. This can cause problems later. Your child may even think that they are being allowed to do whatever they want because they won't get better. Also, if you have other children, they might feel angry and upset if you let the child with cancer behave differently.

### ***Encourage your child to be independent***

Let them feed and dress themselves and brush their teeth. Give your child jobs or chores to do. If they are feeling well, get them to put away toys, fold clothes or set the table. Let your child feel more in control of what is happening to them by allowing them to make decisions when possible. They can decide what healthy snack to eat, what colour pajamas or jeans to wear, or whether to have their temperature or blood pressure taken first.

### ***Have them eat and play as well as they can***

Try to offer healthy food. It will be easier for your child to get through treatment and to recover if they eat well. But don't be too hard on yourself on this one - eating well during treatment is hard even for adults.

Cancer and its treatment are very tiring, even for children. Your child will need lots of rest, but sometimes it will be good for you to encourage your child to be active. Being inactive for long periods of time can lead to feeling even more tired or other problems such as muscle weakness. Active play can also make your child feel a bit happier, so find ways to move when you can. Talk to your healthcare team about which activities are OK. When your child is not feeling well, try simple games like charades or Simon Says or take short walks. Moving and stretching will help you both feel better. Even chores such as folding laundry can help.

### *Teach your child about feelings*

Children of all ages need to know that it's OK to feel mad or sad sometimes. Provide safe ways to express anger and other feelings using things like playdough, painting, building blocks, talking, physical activities, writing, music or art. Some hospitals provide programs in these areas.

### *Help them to be creative*

Offer activities like crafts, painting, drawing and music. Ask about expressive art, music and play programs at the hospital. Many children enjoy them, and these activities can also help them talk about feelings. Your child may even be able to try something new.

### *Support learning*

At home, when possible, keep up with lessons, hobbies and other activities. If spending time in hospital, ask to see the hospital teacher or school liaison. They can help your child keep up with school work.



They provide school while the kids are in the hospital, and the teacher was amazing.

### *Limit screen time*

Your child may want to watch more television or spend more time on the computer or phone. Try setting some time limits. Focus on favourite shows, games or movies. Turn off the screen when the shows or games are finished. Make sure the phone gets turned off in plenty of time for rest or sleep.

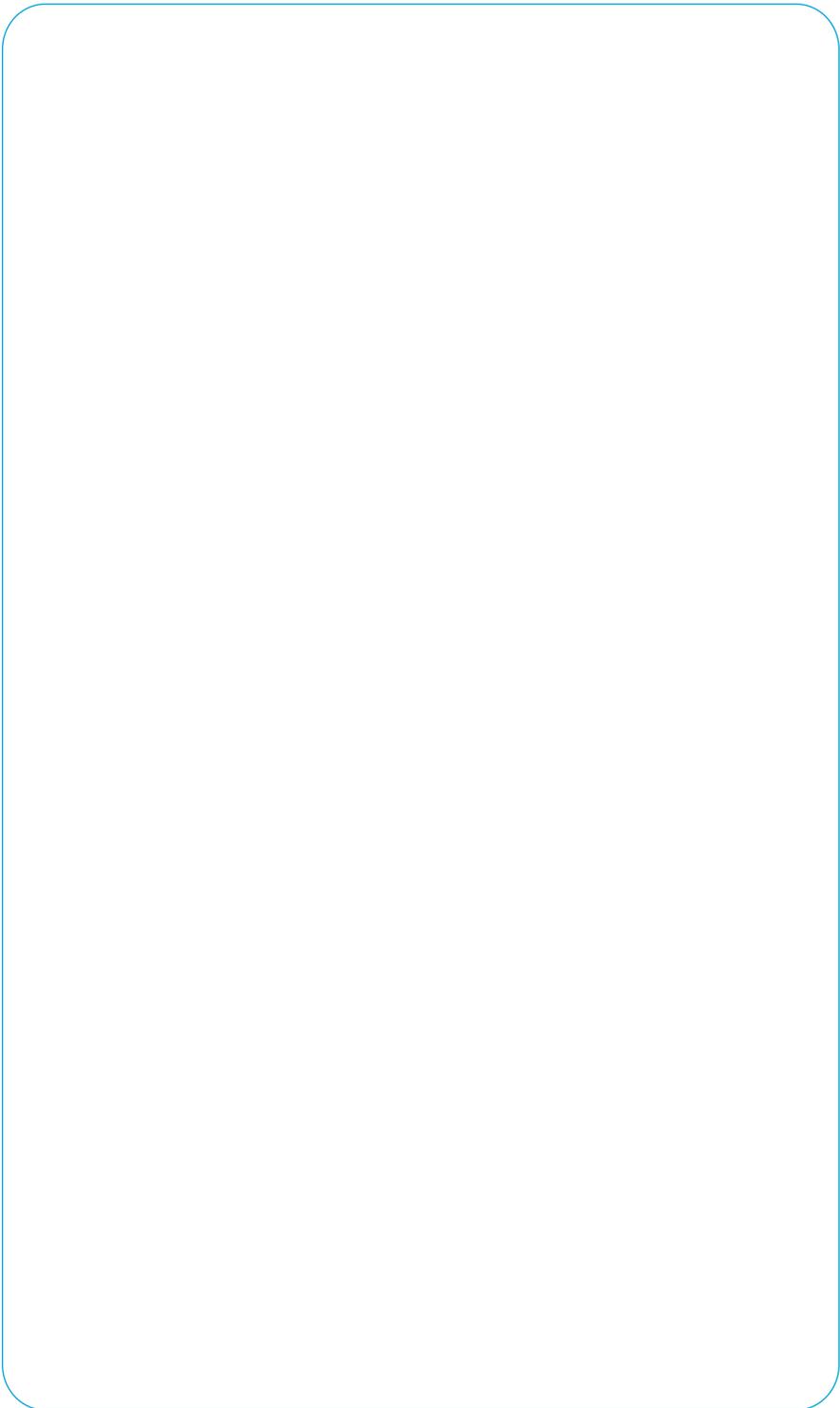
Take breaks to go for short walks. Try other activities like reading, playing games or listening to music, audiobooks or podcasts.

### *Keep them connected to other kids*

Find opportunities for your child to be with other children when they feel well enough. Let brothers, sisters and friends visit if your child is in hospital.

Help everyone keep in touch with letters, emails, phone calls, texts and social media.

“ 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.



# Talking to your child about cancer



Talking to your child about cancer isn't easy, but it is important. What you say and how much you say depends on the age and stage of development of your child. Change the words you use to suit your child's age and understanding.

## Why you should be honest

It's natural to want to protect children from something scary by not talking about cancer. But children can tell from the way everyone is behaving that something is wrong. It's best to talk about what's going on in ways that children will understand. There are many good reasons to be honest.

- Being honest helps your child to trust you and the healthcare team. Children feel more scared when they don't know what's happening to them or why it's happening.
- Being honest gives children the correct information about cancer and cancer treatment. If you don't tell the truth, they use their imaginations to try to understand what's going on. Some children will worry that things are worse than they are.
- If you tell children why they are having treatments (like taking medicine, having lumbar punctures) they may be more willing to cooperate even when treatments are uncomfortable.
- Knowing about their illness and treatment can help children feel more in control at a time when they feel out of control. When they know what's going to happen, they can find ways to cope with treatment.
- If you pretend everything is fine, your child might think they shouldn't talk about their own worries. They might not tell you how they feel or what they need.

## Practical advice on talking - and listening

You're not alone if you have no idea how to start a conversation about cancer. The healthcare team is there to support you and your child. Talk to them about ways to talk to your child.

Whether you're about to have your first talk with your child or are talking again about some topics, these tips can help.

### *Choose a time to talk when you're feeling calm*

It's hard to talk if you are overwhelmed by your own feelings. Practising the key things you want to say in this conversation can help. But don't put too much pressure on yourself to have the perfect conversation. There will be other times to talk.

### *Have someone else with you*

If you are part of a 2-parent family, try to find a time when both parents can be there to support your child and each other. If you are a single parent, think about asking someone else who is close to your child to be there with you. That way, your child will know that there are other adults who will support them.

### *Talk about feelings*

It's normal for children to feel worried, scared, angry or even happy, but it can be hard for them to express these feelings. If you share your feelings in words, you'll show your child that it's OK to talk about them. You could start with, "I'm really sad and upset that you're sick and have to stay in the hospital."

You can also help your child to name their feelings ("You look really angry") and ask open-ended questions ("How do you feel about having an operation?"). Show your child that you are willing to listen and talk honestly.

## *Reassure your child*

Tell them the doctors have a plan to help them get better. Tell them that you will be there to look after them. But don't make promises you can't keep or say things that aren't true. "Yes, the chemo will make you feel sick for a while but the doctors think it will get rid of your cancer." "The needle will feel like a sharp poke, but it will be very quick and I will be there with you."

## *Follow your child's lead*

Asking open-ended questions such as "What do you know about cancer?" will help you find out what your child understands. Talk about any information that is not correct. To find out what else your child wants to know about the cancer or treatment, ask them. This will help you understand the pace your child wants to go at.

Most children find it hard to take in a lot of information all at once. They need time to think about what they have learned before they can understand new information. Tell them there will be lots of chances to talk and ask questions. If they turn away or change the topic, they might need a break. You can talk again another day.

## *Be ready for questions*

Children of all ages have worries about cancer. Reassure your child that questions are OK. Some children may ask you questions right away. Some children need more time to think about what you have told them. Don't worry if you don't have the answers. Sometimes, there aren't answers. You can then talk about why your child has this question or why your child has this question right now.

For many questions, these starting points will help:

- **Did I cause the cancer?** No. Nothing that you or anyone else said, did, touched or ate caused the cancer. Doctors don't know what caused it, but they do know how to try to get rid of it.

- **Did I catch cancer from someone?** No. You don't "catch" cancer from someone else. It's different from a cold. This also means that you can't give it to anyone else.
- **Will I die?** We hope that the medicine will get rid of the cancer and that doesn't happen. Everyone dies sometime - we don't know when it will happen but we hope it is when we are very old.
- **Will it hurt?** Sometimes you will have to have needle pokes that may pinch or sting. Some medicines may upset your stomach, and some days you might not feel well. But doctors and other people on your team will help you.

## Matching your messages to your child's age

Children at different ages and stages of development understand cancer differently. They will have different feelings and reactions to the news that they have cancer and need to be treated. Members of the healthcare team, such as nurses, social workers and child life specialists, can help you talk to your child in a way that suits their age and understanding.

### Advice for all ages

Many experts give this advice on talking to children of all ages:

**Use simple, direct words.** You know your child, and what words they will understand. Try to use or explain the words that your child will hear the healthcare team use. It's confusing to children if they hear different words from different people. Even using simple words, you may have to explain things many times, especially with younger children.

This means not using euphemisms, which are words or phrases people use because they find the real words harsh or scary. These words can be confusing to the child who has cancer and their brothers and sisters as well. For example, if you avoid using the word "cancer" and only talk about your child being "sick," siblings can get the wrong message. The next time a sibling is sick with a cold, they can worry they will have to go to the hospital and have chemotherapy. It is better to use the more precise word, explain it and disconnect it from common words that are part of everyday life.

**Give small bits of information.** Focus on what they need to know now and what they need to know to feel secure. If you are still waiting for test results, talk about what you know so far. "The doctors are doing tests to find out exactly what's wrong so they can make a plan to help you get better. When we find out, we will tell you."

**Think about how your child might understand your words.** Children often understand words literally. Try to explain what words or phrases mean or choose different words to explain new ideas. People often describe general anesthesia as being "put to sleep" but those words might remind children of a pet that was "put to sleep" and worry that they are going to die. If you use the words "bad" or "good" to talk about cancer, children might think they got cancer because they were bad or did something wrong.

## *Babies*

Babies are too young to really understand what is going on, but you may still find it helpful to talk to your baby. In a soothing tone, you might tell your baby, “You are sick. The doctors will give you medicine to help you get better. You have to sleep at the hospital, but I will be with you.”

## *Toddlers*

By the age of 18 months, children understand more about what’s going on around them. Toddlers still don’t know how their bodies work and they sometimes think they make things happen. They might think, “I’m sick because I was bad.” Use very simple words, toys and books to help them understand what’s happening to them.

## *Preschoolers (3 to 5 years)*

Preschoolers understand simple ideas about the body and illness. They can only learn small amounts of information at a time. They often ask the same questions over and over again until they understand the answers. Very young children think everything that happens is related to them. For this reason, they sometimes think they did something to cause their cancer. Tell them that nothing they did caused the cancer.

Give preschoolers simple explanations about cancer and where it is in their body. Tell them what is going to happen during treatment. You might say, “You have cancer. It means that some lumps that shouldn’t be there are growing inside your [name the part of the body]. You are going to have an operation and the doctors will take the lumps out. Then they’ll give you some medicine to make sure the lumps don’t grow back.”

If your child wants to know more about cancer, say, “Your body is made up of trillions of tiny things called cells. They’re so small that you can’t see them. Every cell has a job to do to make your body work and stay healthy. Cancer is a disease that happens when some of the cells in your body get sick. The sick cancer cells can grow into a lump or crowd out the healthy cells and stop them from doing their job.”

Pay attention to your child’s feelings by listening to what they say and by watching when they play. Children often act out their feelings and ideas with toys and games. Most preschoolers can tell you what they think and feel, but they find it hard to express their feelings in words. They often show their feelings in their behaviour, by acting younger than they are, by being aggressive or by clinging to you.

### *School-age children (6 to 12 years)*

School-age children can use words to describe their bodies, thoughts and feelings. They usually understand how their bodies work, but medical words can confuse them. At this age, children can understand that taking medicines and doing what doctors tell them will help them get better.

Tell your child the name of their cancer, what part of the body it is in and what the doctors are going to do to make them better.

School-age children may think they did something to cause their cancer. Tell them that no one knows what causes most childhood cancers. They might also worry that they will die. Talk about those fears. Tell them that the doctors have a plan to help them get better.

## Teenagers

Teenagers can understand more complex information about cancer and cancer treatment. You might say, “The doctors told us you have a kind of cancer called [name]. Cancer is a name for a lot of different diseases that start in your cells. Your body is made up of trillions of cells. Every cell has a job to do to make your body work and stay healthy. When cells get sick with cancer, they might grow too fast or grow the wrong way and don’t do the job they are supposed to do for your body. Different kinds of cancer cells act in different ways and that causes different kinds of cancer.”

Answer your teenager’s questions as openly and honestly as you can. Give them time and space to deal with their feelings. Your teenager can give you the impression that they don’t want you around. But at the same time, they need to know that you’re there, caring for them. It can be hard to strike the right balance between supporting your child and giving them the space they need. They may not want to show their feelings or talk to you about them. Many teens would rather talk to their friends or find information on their own. If they don’t want to talk to you, help them to connect with friends or other adults who can help. Encourage them to talk to their healthcare team about information that they find on their own.



### Need more info?

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) to find out about how children may react to information they are given.

## Creative ways to talk

Not all children want to talk about cancer, or they may not be able to. Very young children and children with special needs might struggle to understand new information. Try these creative ways to talk about cancer:

- Ask your healthcare team if they can recommend picture books, videos or comics to explain treatment to young children. Give older children and teens books or pamphlets to let them read about cancer for themselves.
- Buy a toy medical kit and a baby doll or stuffed animal. Children will often act out what they have experienced. This is a great way to see how your child is feeling and what your child understands about treatment. Playing in this safe way, at home with people they love and trust, can be helpful.
- Make up stories or games to explain cancer and cancer treatment. You could make up stories about fighting the cancer cells using dolls, toys or Lego. Children who play video games can pretend they are zapping cancer cells.
- Use art and music. Ask your child to draw what they think cancer is and how treatments work. Their drawings can tell you a lot about what they understand. Listen to music to help explain treatment. A loud sound like a drum could be the chemo killing the cancer cells. Talk about how falling asleep before an operation is like the feeling they have when they listen to a lullaby.
- Keep a journal or make a scrapbook. This can help older children and teenagers express their feelings and take part in their own treatment.

## Coping with tests, procedures and medicines



Your child will have many different kinds of tests and procedures to help the healthcare team diagnose the cancer, choose the best treatment to try, and see how the treatment is working. The healthcare team may have started with a biopsy or an imaging test, like an ultrasound or x-ray. They may also set up lab tests and body function tests to check your child's hearing, heart, lungs and brain.

## Supporting your child before and during a test or procedure

Most children will cope better if they know what to expect during a test or procedure and how it will help them. Many treatment centres offer tours or programs to help children get ready for operations and other procedures. (Your centre may even offer an online tour.) They might let children visit the operating room or play with medical equipment like stethoscopes and blood pressure cuffs. This helps kids know what to expect.

When Joanne's daughter, Abby, was being treated for retinoblastoma and had to have a test or procedure, Joanne turned to other parents who also had children in treatment. Even if their child had a different diagnosis, their child might have had the same test in the same hospital. She would come away with information and often with something she could try.

“ I talked to other parents. They know what you're talking about, they've gone through similar situations. If not the same diagnosis, their child is still in the hospital. They know about the different procedures and treatments. Your child can get so uncomfortable during some of the stuff. Certain medications work for one but not for others. You get a chance to discuss that and learn what might work and what else you can try for certain situations they don't necessarily tell you in the hospital.

## > **TIPS** for supporting your child

Children often feel stressed or scared for a long time before a test or treatment. You can help by preparing your child before they actually get to the procedure room.

- Tell your child which part of their body will be involved in the test or procedure.
- Tell them how and where the test will be done.
- Talk about what your child will hear, see, smell, feel and even taste during the test or procedure.
- Let them know it's OK to cry or make a noise.
- Encourage your child to ask questions and tell you what they are worried about.
- If your child asks whether the procedure will hurt, describe what they might feel. For example, a needle might pinch, prick or sting.
- Help your child learn and practise simple relaxation techniques, such as breathing deeply and evenly or using visual imagery. For example, have your child picture themselves in a safe, relaxing or fun place.
- Distract your child from pain or feeling uncomfortable by giving them something fun or relaxing to focus on. Depending on your child's age and what's allowed during a test or treatment, you might blow bubbles, read a book, listen to music, or play with a toy or game.

- Let your child feel more in control by making choices. They might be able to choose an arm for a needle, pick the flavour of the anesthetic or decide whether to sit or lie down during a test.
- Give your child a simple job to do like holding a bandage.
- Let your child hold a favourite toy or blanket, if possible.
- If you can't stay with your child during the test or procedure, tell them who will look after them, where you will be during the procedure and when they will see you after it is over.



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



### **Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) for age-specific tips to help your child cope with tests and procedures.

## Sedatives and anesthetics

To avoid pain or discomfort or to help your child keep still for a test, your healthcare team may suggest a sedative or an anesthetic for your child.

A **sedative** is a drug used to calm children down, ease their anxiety and help them sleep. It can be used for procedures when the child must stay still for long periods of time (such as imaging tests).

An **anesthetic** is a drug that causes the loss of some or all feeling or awareness.

Local anesthetics cause numbness or a temporary loss of feeling in one part of the body. Your child stays awake during the procedure, but has no feeling in the part of the body treated with the anesthetic. A local anesthetic may be used to numb the skin before a needle or surgical cut. It may be given as a cream, a needle or both. Anesthetic creams numb the skin and tissue about 0.5 cm (1/4 inch) under the skin. After the cream has numbed the surface of the skin, a needle may be used to give anesthetic to numb the deeper tissue.

A general anesthetic drug causes a loss of consciousness. It may be described as being asleep. Under general anesthesia, your child is completely unaware of what is going on and will not feel any pain.

## Helping your child take medicines

Medicine is given many different ways – by IV (intravenous), by needle injection or by mouth. Some children find it hard to swallow pills, capsules or liquid medicine, especially if they don't taste good.

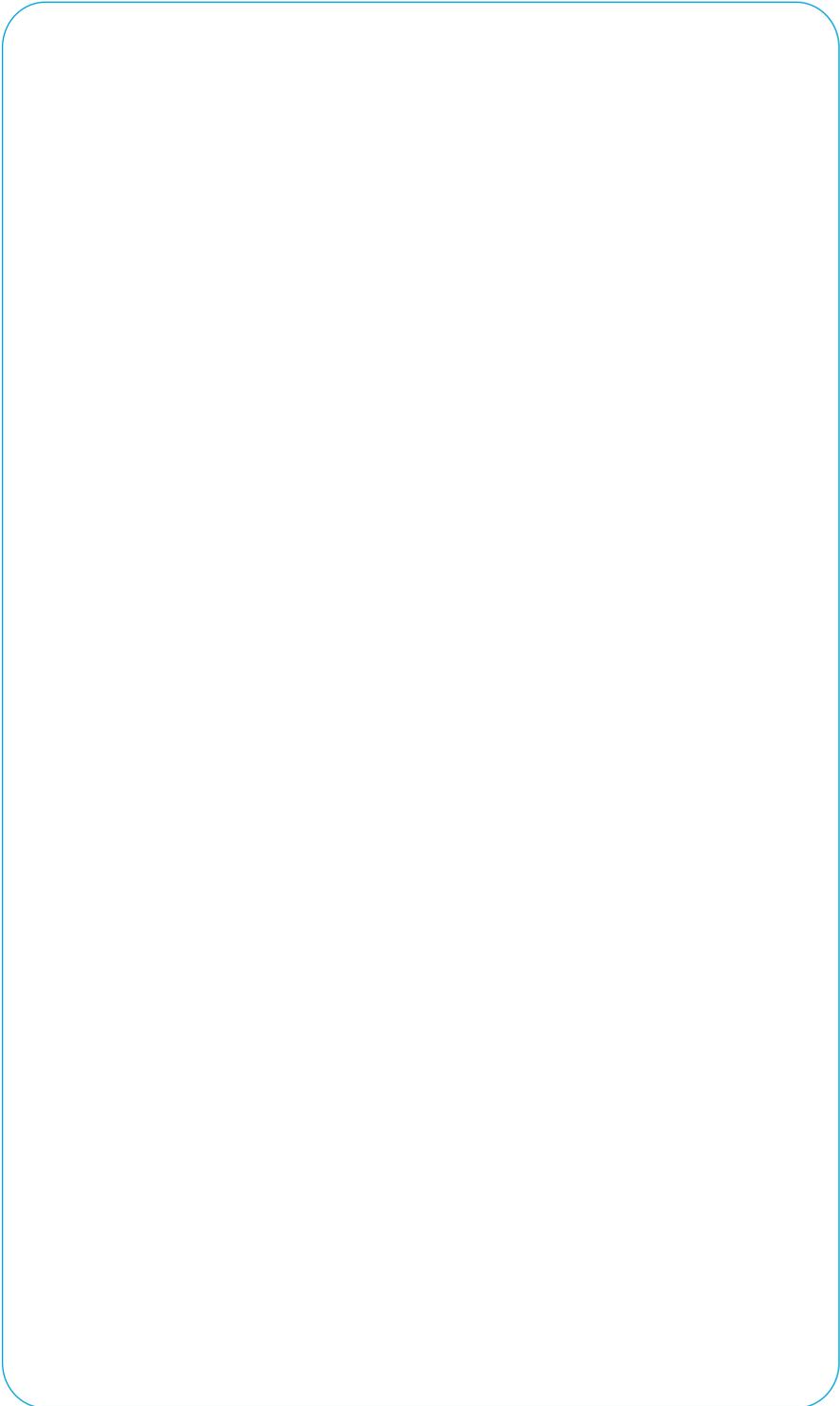
### > **TIPS** to help your child take medicines

- Ask your nurse or child life specialist at the hospital for any tips and tricks they've learned over time.
- Ask your pharmacist if there are different forms (liquid, capsule or pill) or flavours of the medicine that your child could try. Ask whether you can crush pills or empty out the capsules.
- Make taking medicine part of your child's normal daily routine. Be positive, firm and consistent. Explain why the medicine will help your child get better.
- Be honest and sympathetic. For example, say, "I'm sorry it tastes so bad."
- Offer a choice that gives your child some control. For example, say, "It's time to take your medicine. Would you like water or milk to help you swallow it?"
- Give your child ice chips or a popsicle just before they take the medicine. Cold helps numb the mouth and taste buds and can help hide a bad taste.
- Use an oral syringe for liquid medicines and try to get the liquid toward the back of the mouth. Let your child help to push the plunger and swallow the medicine a little at a time.
- Praise your child for taking the medicine without a lot of fuss.

## **Taking medicine at home**

When you have to give your child medicine at home, be sure to ask the pharmacist to tell you all about the medicine, including:

- name, purpose and dose of the medication
- how and when to give the medicine
- if the medicine can be given with or mixed with food
- if there is anything your child should not do or should not eat when they take the medicine
- possible side effects and what you should do if they happen
- what you should do if your child won't take the medicine, vomits the medicine or misses a dose



# Pain



Preventing or managing pain is an important part of treating your child. The healthcare team is there to help. Pain related to cancer may be caused by the tumour itself, procedures used to treat cancer or side effects of treatments.

## What to watch for

Not all children with cancer have pain, but if you think something isn't right and your child has pain, talk to your child's doctor. Trust your judgment and what you see as a parent. Signs of pain vary by age, but be alert to these signs of pain in children.

**Very young children:** Babies and young children show discomfort by crying when touched. They may cry more often or their cries may sound different. Other signs of pain include not being able to be comforted or being withdrawn or tense. A change in sleeping or eating patterns or tugging at a part of the body may also be signs of pain in young children.

**Older children and teenagers:** Older children and teenagers can tell you if something hurts. But they may not want to because they don't want to upset you or they don't want more tests or to return to the hospital. Their body language may tell you they have pain. They may stand very still and quiet or they may guard or protect the part of their body that hurts. Older children who have pain may grimace or make faces that show they are in pain. Their eyes may be red or puffy from crying.

Children who have disabilities may not show pain in the same ways as other children.

“ The other issue I thought was never properly dealt with was his autism ... He was very quiet, his face would show no emotion so they took that as he was fine. But really he was locked in a prison and he couldn't get out. He was so sick and so anxious and feeling so terrible he couldn't express himself.

If your child has a disability, try these other ways to understand their pain:

- Pay attention to your child's mood (for example, if they are cranky).
- Watch your child's behaviour to see if it changes (for example, if they look for ways to feel more comfortable or point to or touch the part of the body that hurts).
- Look for changes in your child's eyes, like avoiding eye contact or looking distracted.
- Watch for changes in your child's activity level.
- Watch to see if your child cries or gasps.

## Helping your child talk about pain

Children express pain differently depending on how old they are. Babies can show you by kicking and screaming. Toddlers and preschoolers can usually use simple words like “owie” or “hurt” to tell you they have pain, and something about how much it hurts and where it hurts. Older children and teens can usually describe their pain in more detail.

Here are some questions you can use to talk to your child about pain. Change the words you use to suit your child’s age and understanding:

- Do you have a hurt/owie/pain?
- Can you show me where it hurts? Does the pain go anywhere else in your body?
- When did the pain start? How long have you had it?
- Do you know what might have started the pain?
- How much does it hurt?
- Can you tell me how the pain feels? Suggest words like sharp, dull, achy, pins and needles, burning.
- Can you think of anything that would help to take away the pain? Suggest medicines the child has had before or other things that helped.

## *Measuring the pain*

Find ways to help your child tell you how much the pain hurts. Your nurse or child life specialist can help you find a scale that will suit your child’s age and understanding. Here are some examples:

- Which face shows how you feel? (using a pain scale of faces ranging from happy to very upset)
- What number is the pain from 1 to 10? (where 10 is the worst the child can imagine and 1 is no pain at all)
- Show me with your hands how big the pain feels.
- Does it hurt a little, a medium amount or a lot?
- Is the pain as big as a mouse, a dog or a lion?

## How you can help your child cope with pain

You can't always make the pain go away, but there are many ways to make your child feel better.

### > TIPS

- Be with your child. Children who are in pain feel more scared if they are alone.
- Try to stay calm yourself. If you look calm, your child will feel more relaxed. Try talking, breathing and moving more slowly. This will help you feel calmer.
- Ask your child to tell you about the pain and how much it hurts. Talking about it can help.
- Be honest. Never say something won't hurt if it will.
- Find ways to distract your child from pain. Depending on your child's age, try blowing bubbles, squishing playdough, reading a book, watching a movie, listening to music or playing a game.
- Praise your child for using a way to cope with the pain. For example, say, "You did a really good job of taking deep breaths when the doctor did the spinal tap."

### Relaxation techniques

Some healthcare professionals can teach you and your child about ways to relax. This can help with pain during procedures. You might try:

- listening to slow, quiet music
- taking slow, deep breaths
- meditating with focus on an object, sensation or phrase
- imagining or remembering a place or activity that makes your child happy

*"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."*

## How the healthcare team can help

If your child is in pain, ask your healthcare team for help. Pharmacists, anesthesiologists, child life specialists, psychologists and music, art and recreational therapists all know about different ways to cope with pain. They will work with you and your child to find the best ways to help your child cope with pain.

“ 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 deal with his anger. She used toy soldiers to map out his anger for him so he could talk about what he was feeling and how to cope with it. That really helped.

### *Humour, art, play and music therapy*

Many centres have staff and volunteers who offer humour, art, play or music activities. These activities can help distract children from pain and may help them feel better. Taking part in these activities can help children express their feelings and worries and learn new ways to cope with pain and discomfort.

### *Pain medicines*

Your child's doctors and nurses may use medicines to help block or reduce the physical pain that your child feels. Different medicines work better for different types or causes of pain and for different levels of pain. It's better to try to treat pain right away because your child will need a lower dose of pain reliever than if you wait until the pain gets worse.

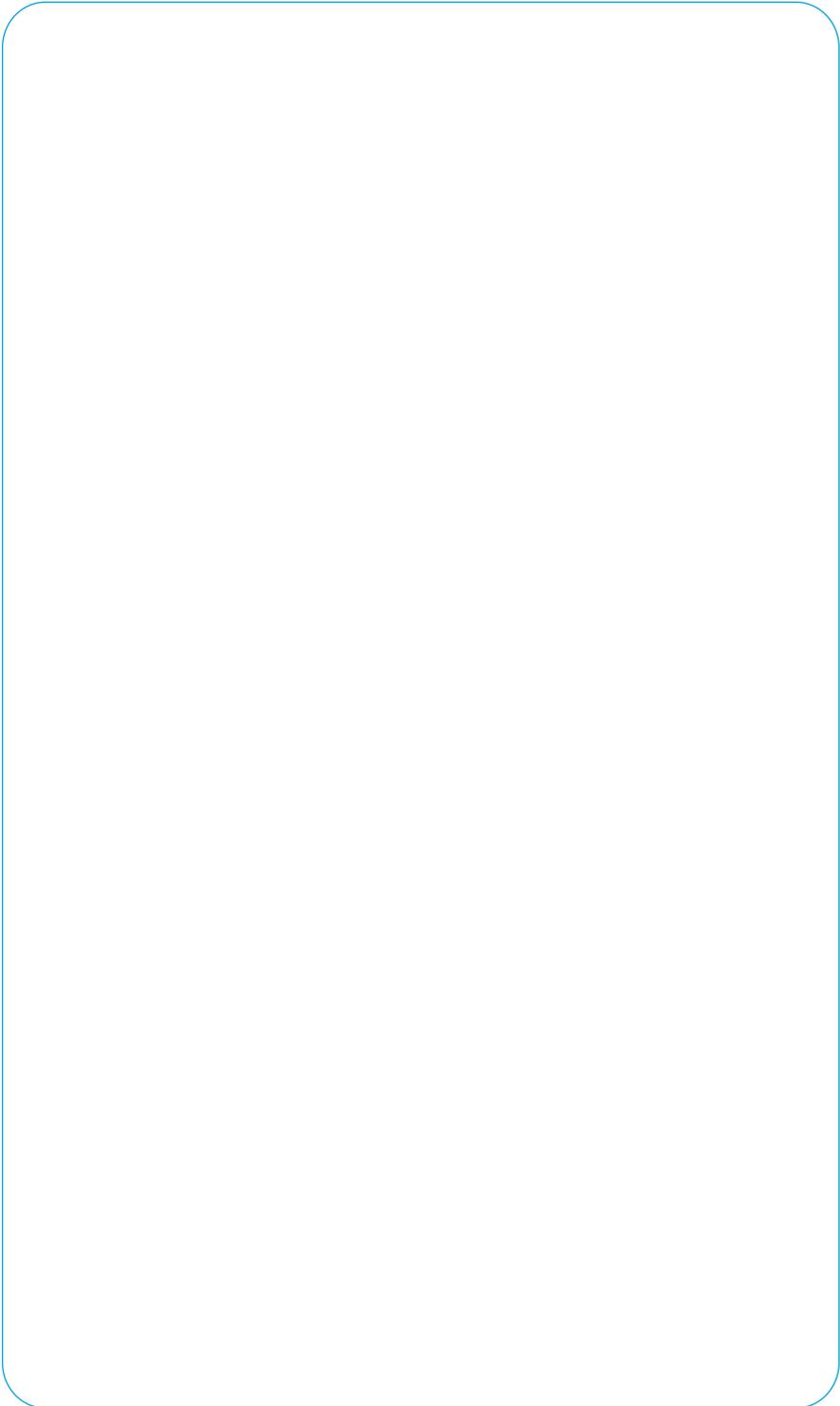
Doctors often start to manage pain by using weaker medicines like acetaminophen (Tylenol). If these don't work, they will add stronger medicines like opioid drugs (morphine, oxycodone).

Sometimes, parents worry that taking stronger medicines will lead to addiction. But taking medicine to control pain is very different from addiction. Addiction happens when the need to take a drug becomes a craving or an impulse that is more than just physical. Addiction to drugs used to treat cancer pain is rare.



### **Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) for more information on pain in children and how to cope with it.



# Managing side effects



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 is there to help if you're worried about any side effects. They will also tell you about anything that needs to be reported right away.



Every time he was to start a new med, the hospital pharmacist provided papers that explained why the med was being used, what it was going to do and possible side effects. The pharmacist then sat down with me and went over everything. That was so helpful and reassuring. The nurses also verbally provided awareness on possible side effects and suggestions on how to deal with them should they appear.



Many parents worry about what their child eats – or doesn't eat – during treatment. We asked our online community how they coped with eating-related side effects. Look for this symbol to see their ideas.

## Anemia

Anemia is when you don't have enough red blood cells. Red blood cells carry oxygen to all parts of the body. When you don't have enough, your body tissues don't get enough oxygen to do their jobs properly.

Some treatments can reduce red blood cells and cause anemia. Talk to your child's healthcare team if your child is very tired, dizzy or short of breath or if they are pale or feel weak or cold. These are all symptoms of anemia.

Anemia may happen in between treatment sessions or once treatment is done. If your child needs help building up red blood cells, the doctor may:

- Change the drug dose they get in each treatment.
- Offer medicine to increase red blood cells.
- Suggest a blood transfusion.
- Delay treatment.

## > Tips

- Make sure your child gets plenty of rest to help keep up energy levels.
- Do the most important activities first before your child gets tired. If possible, let your child help decide what matters most.
- Help your child move slowly. This will help with dizziness. For example, have your child sit on the side of the bed for a while before standing up.
- Offer foods high in iron such as red meats, dried beans or fruit, almonds and enriched breads and cereals.

## Behavioural changes

When children face a stressful situation like having cancer, their normal behaviours might change. They might become more dependent on parents or other adults. Some act younger than their age and return to habits or behaviours you thought they had grown out of, like using baby talk, sucking their thumb or having tantrums.

In addition, some medicine makes children feel anxious, restless and dizzy or makes them have trouble sleeping. Some children get headaches or find it hard to concentrate on anything. All these things can make children feel moody or irritable and behave differently than they usually do.

Tell someone if your child's behaviour changes in a way that causes a problem for you or for them. Work with your team to find ways to help your child express strong feelings and to cope with cancer and treatment.

## Bladder, kidney and urinary tract changes

Some chemotherapy drugs can affect the bladder or kidneys. These organs take waste from the body, including waste from the drugs your child is taking. Some chemotherapy drugs may make your child's urine change colour, look cloudy or smell different.

### > TIPS

- Give your child plenty of fluids. Ask your healthcare team how much fluid your child needs each day. Try water, milk, juice, caffeine-free drinks, broth, soup, ice cream, jello and pudding.
- Have your child drink in small sips throughout the day. Drinking too much at one time may upset their stomach.
- Encourage your child to empty their bladder often. This may help prevent urinary tract problems.

### When to call the healthcare team

Call the healthcare team if your child has any of these signs of a bladder, kidney or urinary tract infection:

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

## Bleeding and bruising

Chemotherapy can affect the body's ability to make platelets. Platelets are 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 small cut. Platelet levels are checked during treatment. If the platelet count becomes extremely low, your child may need a platelet transfusion or the doctor may change the drug dose.

Some over-the-counter medicines, such as cold remedies, pain relievers, vitamins or herbal remedies, can also affect platelets. Talk to the healthcare team or pharmacist before giving your child any over-the-counter medicines.

### **When to call the healthcare team**

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

- bruising easily or red spots under the skin
- bleeding from the gums or nose
- a lot of bleeding from a small cut or injection site
- blood in the stool or black-coloured stool
- blood in the urine or red-coloured urine
- vomiting blood or vomiting something that looks like coffee grounds
- bleeding from the vagina that is different from your daughter's normal menstrual period (for example, a period that is heavier or lasts longer than normal)

### **> TIPS**

- Don't give your child ibuprofen (for example, Motrin or Advil) or any medicines containing Aspirin unless your doctor says to. They decrease the blood's ability to clot.
- Avoid contact sports and other activities where your child might get hurt easily.
- Use a very soft toothbrush or cotton swabs for brushing teeth. Soften the brush with hot water before each use.
- Be very gentle and careful when flossing. Avoid areas that bleed easily. Your healthcare team may recommend that your child avoid flossing until platelet counts return to normal.
- 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. If bleeding 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 bum (rectum). If you have to check your child's temperature, do it by mouth or ear.

## Constipation

Constipation happens when the stool becomes dry and hard, making it hard to have a bowel movement. Pain medicines, some chemotherapy drugs, radiation to the stomach area or the location of a tumour can all cause constipation. Constipation can also happen because your child's eating habits have changed, they're drinking fewer liquids or they're less active.

If your child is constipated, your healthcare team may suggest a stool softener or laxative. Talk to your healthcare team before giving an over-the-counter laxative.

### > TIPS

- Serve more high-fibre foods, but a little at a time. Examples of foods with high fibre are whole-grain breads and cereals, vegetables, fruit (including dried fruit), legumes, seeds and nuts.
- Add extra vegetables and fruit to your child's food. You can add fruit to smoothies, jello and other desserts, or serve it with yogurt, pancakes and waffles. Try adding extra vegetables to soup, pasta sauce, salads or sandwiches. It's OK to use the blender or food processor to hide vegetables in foods that your child likes such as spaghetti sauce, chili, curry or casseroles. Add puréed fruit or shredded veggies to muffin mixes and pancake batters.
- Check the labels on cereal boxes. Look for more than 4 grams of fibre per serving.
- Sprinkle bran on cereal. Start by adding 10 mL (2 teaspoons) a day and gradually increase the amount to 30 mL (2 tablespoons) a day.
- Give lots of fluid throughout the day. Try water, milk, soup, or fruit or vegetable juice. Hot or warm liquids like cocoa, tea or lemon water can also help.
- Offer foods that are natural laxatives like prunes, rhubarb and papaya.
- Encourage your child to be more active, if they are able. Just taking a short walk can help.

## Diarrhea

Your child may have loose or watery stools as a side effect of cancer treatment. It's important to tell your healthcare team if your child has diarrhea because it can cause other problems, such as fatigue, weight loss or the loss of too much water from the body (dehydration). Talk to someone on the team before giving your child any over-the-counter medicine for diarrhea. They can tell you what to give and when, depending on what's causing the diarrhea.

### > TIPS

- Offer plenty of non-carbonated, caffeine-free fluids such as water and clear broth. They will help prevent your child from becoming dehydrated. Sports drinks may also help but check with the nurse or dietitian first.
- Serve foods that are low in fibre. Examples include white bread and pasta, bananas, melons, applesauce, mashed potatoes or baked potatoes without the skin, meat, poultry and fish.
- Choose salty foods like soups, sports drinks, crackers and pretzels to replace sodium and other nutrients (electrolytes) lost from the diarrhea.
- Offer foods that are high in potassium such as bananas, oranges and fruit juices.
- Limit greasy, fried, spicy or sugary foods.
- Avoid sugarless gum and candies made with sorbitol, which acts like a laxative.
- Don't give foods that are natural laxatives. These include prunes and prune juice, rhubarb and papaya.
- Limit milk and milk products if they make the diarrhea worse.
- Continue to breast-feed infants.
- Give liquids between meals and increase fluids after each loose stool.

- Keep your child quiet after meals with quiet play or a nap to slow down bowel action.
- Resume your child's normal diet gradually once the diarrhea goes away.

### **When to call the healthcare team**

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

If your child can't drink enough or is losing too much water because of vomiting or diarrhea, the healthcare team can give extra fluids and electrolytes intravenously (directly into the blood through a vein).

## Dry mouth

Some children get very dry mouths from cancer treatments and medicines. This can make it hard for them to eat.

### > TIPS

- Offer moist foods and drinks with meals or snacks to help your child swallow more easily.
- Add moisture to solid foods by adding broth, soup, sauces or gravy. You can also blend foods into a purée.
- Make sure rice is well cooked.
- Encourage your child to take sips of fluid when they eat to make chewing easier.
- Have your child sip fluids often throughout the day. Try water, juices and nectars, soups, milk or milk products, popsicles, jello and pudding. But limit soft drinks that have caffeine, such as cola. Caffeine can dry out the mouth.
- Offer cut-up frozen grapes, strawberries or blueberries, or popsicles.
- Offer your child sweet or sour foods. These foods help stimulate saliva production.
- Use a cool-mist humidifier at night.



Use frozen fruit to cool a dry mouth.  
It also takes away pain from mouth sores.

### A dry mouth can lead to tooth decay

It's important to take extra care of your child's teeth and mouth during cancer treatment.

- Your doctor or dentist may recommend using a fluoride mouth rinse or gel. Check with your doctor before buying a mouthwash. Many contain alcohol that dries out the mouth even more.
- Children, especially those having radiation therapy, should rinse their mouths often during the day. Your healthcare team can recommend a recipe.
- To care for infants' and toddlers' mouths, wrap a soft cloth around your finger and gently wipe the teeth and gums with the mouth rinse. Soft oral swabs (available in drugstores) can also be used to apply a mouth rinse to the child's mouth and gums.

## Fatigue

Fatigue is a feeling of being very tired. Your child may feel weak, heavy or slow, and they may have trouble concentrating or remembering things. Fatigue is different from feeling tired after a long day. It may not get better with rest or sleep. Many things can cause fatigue, such as treatment, low blood counts, changes to eating habits, fever, pain and worry.

Most children experience fatigue during treatment. Tell your healthcare team when your child feels most tired, when they have energy and if sleeping helps them feel rested or not. It's possible that they may need medicine, a nutritional supplement or a blood transfusion.

Fatigue usually goes away over time after cancer treatment ends. But it can take a long time to go away completely.

### > TIPS

- Try to schedule appointments or activities your child enjoys when they have the most energy.
- Plan ahead. Do the things that mean the most to them first. Plan rest periods before activities. Plan shorter outings and play dates.
- Offer healthy foods every few hours when your child is awake.
- Rearrange your home so that many activities can be done on one floor.
- Ask your healthcare team to suggest exercises or activities that may be right for your child. Being active in some way can actually give your child more energy.
- Have your child rest when they need to – short naps of 10 or 15 minutes rather than longer naps during the day. Too much rest, as well as too little, can make them feel more tired. Save their longest sleep for the night.
- Try to have a regular bedtime routine.

## Food battles

Parents and children often disagree about food, but when a child is sick with cancer you might worry even more about making sure your child eats well. You can't control the cancer or treatment, so it's natural to try to control what your child eats. It's not that surprising that many children try to do exactly the same thing – control what they eat.

### > TIPS

- Find healthy foods that your child likes and serve them often. Offer foods like vegetables or fruit first when your child is most hungry.
- Don't worry too much if you're serving the same thing a lot. Variety is important, but so is getting enough calories – without food battles! If your child is eating healthy food, it's OK to serve the same thing again and again.
- Offer small portions. Large portions of food can overwhelm your child. Too many choices may also be overwhelming.
- Keep mealtimes to 20 minutes. Remove the food when your child loses interest.
- Serve meals and snacks at regular times. Routine is important.
- Be flexible – remember that there is no “perfect” or “magic” diet for children with cancer.

## Food cravings and dislikes

You may find that your child suddenly craves some foods or won't eat foods that they used to enjoy. These cravings and dislikes can change over time, even from day to day. There will be times when you'll do just about anything to get your child to eat. If your child is refusing healthy foods, especially when feeling unwell, it's OK to offer foods that are less healthy. Kids being treated for cancer need to get enough calories.

### > TIPS

- Offer healthy foods and foods your child likes when their appetite is good. Dislikes will pass.
- Use food cravings to your advantage by including the foods your child craves in healthy meals and snacks. For example, chocolate can be used in a milkshake, in banana bread or as a dip for fruit.
- Keep favourite snacks around to nibble on when your child doesn't feel like eating a full meal.
- Take a break from favourite foods when your child is feeling nauseous or vomiting. This will keep your child from linking these foods to feeling sick.
- Add extra seasonings if foods taste too bland or to mask unpleasant tastes.



Her taste would change. So for example, raspberries were fine for 4 days and we bought pints of them to follow her taste change. Then, suddenly she couldn't eat them at all.

## Hair loss

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

Parents of young children often care more about hair loss than their child does. But school-age children and teens may find it very upsetting to lose their hair. Siblings often worry that their brother or sister will be teased about this side effect.

There's nothing you can do to prevent hair from falling out but the loss is usually temporary. Hair grows back when the cancer treatments are done, or in some cases, when the treatment becomes less intense. The hair may be a slightly different colour or texture (curlier, thicker or thinner) than before the cancer treatment.

## > TIPS

- Find out whether your child's treatments will lead to hair loss. If yes, talk to your child about their hair falling out before it happens. This will give you time to prepare.
- Ask your child about what to do to prepare. If your child agrees, you might cut the hair short before it starts to fall out. Some children choose to shave their heads completely to avoid dealing with the gradual hair loss.
- Stay warm during cooler weather. Have them wear a scarf, bandana or hat. Help them choose something they like that feels comfortable.
- Have your child's picture taken before the hair falls out to show how their hair usually looks. 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 soft hairbrush. Put the hair dryer on low heat or let the hair dry naturally.
- Avoid colouring, perming or straightening hair during treatment.
- Avoid using hair dryers, hot rollers and straighteners.
- Protect your child's scalp from sun. A wide-brimmed hat can help. Use a broad-spectrum sunscreen with a sun protection factor (SPF) of at least 30 on their scalp when they are outside.
- Ask about school rules on wearing hats indoors. You may be able to get the rule waived for your child's class. This can help your child feel supported and less self-conscious.

## Infections

Your child is more likely to get infections if they don't have enough white blood cells. White blood cells are part of the body's immune system. They defend the body against viruses and destroy bacteria. Many cancer treatments lower the number of white blood cells in the blood.

Your child's white blood cell count will be checked often during treatment. If they don't have enough white blood cells, the healthcare team may suggest:

- a drug to help increase your white blood cells
- an antibiotic to fight infection
- delaying treatment for a period of time
- a lower dose of drugs

Children who have had stem cell transplants have a 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.

### **When to call the healthcare team**

If your child has any of these signs of infection, call the healthcare team right away:

- a fever
- unusual sweating
- diarrhea
- a burning feeling when urinating
- a severe cough or sore throat
- chills or shivering
- white patches or coating in the mouth

Talk to the healthcare team before giving your child any medicine for a fever. Your healthcare team will tell you more about temperatures and may want you to take your child's temperature in a certain way, such as in the armpit, ear or mouth.

## > TIPS

- 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.
- Tell 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. Ask people not to visit if they or their family members have a cold, flu or other infection.
- Use cuticle cream or cuticle remover instead of tearing or cutting the nail cuticles.
- Give your teen 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 and cover with a bandage.
- Avoid using hot water when your child is bathing or showering. Gently pat the skin dry instead of rubbing it briskly.
- Use a moisturizer or oil if your child's skin becomes dry or cracked to soften it and help it heal.
- Remind your child to wipe their bum gently but thoroughly after a bowel movement. Try using moistened wipes instead of toilet paper.
- Check with the healthcare team before your child has a vaccination or flu shot.
- Avoid contact with anyone who has 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, which occur in both the mouth and throat, are a common side effect of chemotherapy and radiation therapy. They can be very painful and make it hard for your child to eat or drink. Your doctor may suggest a pain medicine or anesthetic cream for the mouth sores. If you use something like this before meals, it will be easier for your child to eat.

### > TIPS

- Offer soft, bland food that is cool or lukewarm rather than very hot or cold. Also avoid very hot or cold drinks. Try soup, mashed potatoes, yogurt, eggs, custard, pudding, cooked cereals, ice cream, casseroles, milkshakes and baby food.
- Have your child use a straw when they drink.
- Try fruit nectars like pear, peach or apricot rather than orange juice or lemonade, which is acidic.
- Limit foods that are tart, salty or spicy or have rough edges (like toast and hard tacos).
- Have your child use a mouth rinse recommended by your doctor or dietitian after eating.
- Use cotton or glycerine swabs (available in drug stores) to clean teeth and help remove pieces of food from the mouth.
- Try a lanolin lip ointment if your child has dry lips that are cracked or irritated.



Smoothies – sometimes I could sneak in an avocado, but usually [I made them] with yogurt, milk and juices with fruit.

## Nausea and vomiting

Chemotherapy and radiation therapy can 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. Pain medicine, constipation or dehydration may also cause nausea.

It's easier to prevent nausea than to treat it once it starts. Your child's doctor can prescribe anti-nausea drugs that your child can take before treatment and for a few days after. Different anti-nausea drugs work for different children, and your child may need more than one drug to feel better.

### > TIPS

- Offer bland, starchy foods. 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 foods that are easy to digest such as soup broth, clear liquids, soda crackers, toast, white rice, pretzels, dry cereals, jello, arrowroot or digestive cookies.
- Have your child sip water and other liquids (ginger ale, sports drinks, broth or herbal teas) throughout the day. Cool or lukewarm liquids may be easier to drink than hot or cold liquids.
- Avoid foods that are very sweet, greasy, fried or spicy or that have a strong smell.
- Avoid vegetables that produce gas, such as broccoli, cauliflower, cucumbers, green peppers and cabbage.
- Serve food at room temperature or colder.
- Keep your child away from the smell of cooking and food preparation.
- Encourage your child to rinse their mouth often with water or club soda to get rid of bad tastes.

## **When to call the healthcare team**

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, even if your child is taking anti-emetics as directed, if:

- you think your child might be dehydrated
- your child can't stop vomiting
- vomiting continues more than 24 hours after treatment

## Skin changes

Some cancer treatments can cause skin problems or make your child's skin more sensitive and more easily irritated. Some cancer treatments can also make the skin very sensitive to the sun. Most skin problems go away once the cancer treatment finishes.

### *When your child is getting chemotherapy*

Chemotherapy medicine can cause rashes, redness, itching, peeling, dry skin and acne. Some drugs can also cause changes in skin colour or changes to fingernails and toenails.

#### > **TIPS** for skin changes from chemo

- Wash your child's skin often with a mild soap 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.
- Keep their nails short and clean. 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. If they do cut or scrape the skin, clean the area at once with warm water and soap.
- Don't squeeze or scratch pimples. Avoid anti-acne skin products. They have chemicals that can dry out the skin.
- Protect your child's skin from the sun with a wide-brimmed hat and tightly woven clothing that covers their arms and legs. Apply a broad-spectrum sunscreen with a sun protection factor (SPF) of at least 30 when going outside. They may need to use zinc oxide to fully block out the sun.

## *When your child is having radiation therapy*

Radiation therapy can cause a reaction that is like sunburn in the area of skin that is being treated. The reaction may be worse or better, depending on the dose of radiation and on how sensitive your child's skin is to the radiation. Some children have no skin problems at all.

### > **TIPS** for skin changes from radiation

- Follow the bathing instructions suggested by the radiation therapy team.
- Ask a member of the radiation therapy team to recommend products like soap, shampoos and lotions that will not irritate the skin or interfere with treatment.
- Check with someone on your child's team before you use any powders, creams, perfumes, aftershave, deodorants, body oils, ointments or lotions on the area of skin that is being treated.
- Have your teen use an electric shaver instead of a razor to prevent cutting the skin in the treatment area.
- Talk to the radiation therapy team if skin in the treatment area gets cut or scraped. They will suggest ways to take care of cuts and scrapes. They can also tell you how to bandage cuts if needed, such as using tape made for sensitive skin and applying tape outside the treatment area.
- Do not put anything hot or cold (such as heating pads or ice packs) on the area being treated.
- Don't squeeze or scratch pimples.
- Cover treated skin with a hat or clothing before going outside. Skin in the treatment area will be sensitive to sunlight and may burn easily. Ask the radiation therapy team about using a sunscreen and when it is okay to start using it.
- 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.

## Sleep problems

Some children with cancer have trouble sleeping (insomnia). They might have trouble falling asleep or staying asleep. Others might fall asleep at the wrong times or sleep too much.

Pain, anxiety, depression and some medicines can affect sleep. Insomnia makes it harder to cope with other side effects of treatment. It can affect your child's mood and energy level, cause fatigue and make it hard to think and concentrate.

Talk to your healthcare team about medicines to help your child sleep. Talk to them about any symptoms that may be causing problems with sleep, such as pain.

### > TIPS

- Try to keep a regular bedtime routine.
- If possible, encourage your child to do something active each day.
- Have your child take only short naps during the day. If they need to rest, have them nap for only 15 to 20 minutes.
- Talk with your child about any fears and concerns they might have. Do this during the day to help them feel more relaxed at night.
- Offer a warm, non-caffeinated drink before bedtime.
- Don't let your child use screens (phones, tablets and computers) before bedtime. Light from screens tricks the brain into thinking it's daytime, making it harder for your child to fall asleep and have a deep, restful sleep.
- Help your child relax before bedtime – have a warm bath, listen to soothing music or read.

## Taste and smell changes

Cancer treatments can change the way some foods taste and smell. Your child may find that some food tastes bitter or metallic or doesn't have as much flavour as before. Familiar foods may taste different or unpleasant. The smell of food cooking may make your child feel sick. These taste and smell changes might mean that your child doesn't feel like eating and begins to lose weight or doesn't eat enough healthy food.

### > TIPS

- Have your child rinse their mouth before and after eating. This will help clear their taste buds. Your healthcare team may suggest using club soda or different solutions of salt, baking soda and water.
- Serve foods cold or at room temperature. This will help reduce strong tastes and smells.
- Add favourite seasonings and spices to make food taste better. Try onion, garlic, chili powder, barbecue sauce, mustard or ketchup, and herbs like basil, oregano, rosemary and mint.
- When food tastes metallic, try using plastic cutlery and glass cooking pots.
- When food tastes bitter, try sweet. Add a little honey or sugar to foods or add sweet fruit to the meal. Offer ginger ale or mint tea.
- When food tastes too sweet, add a little salt or lemon juice. Dilute fruit juices and other sweet drinks with water or ice. Try vegetables instead of fruit.



For a very long time, salty and cheese were 2 flavours that worked for her. I heard this from other parents too. Sweet was really bad ... she couldn't handle anything sweet at all.

## Weight gain

Sometimes, children gain weight during or after cancer treatment. Steroid medicines (for example, prednisone and dexamethasone) are often used and can be very important in cancer treatment. But they can make your child feel hungry more often, which can lead to weight gain. Some children also gain weight because they are less active or snack more because it makes them feel better and gives them something to do when they are sick.

Try these tips to help your child maintain a healthy weight during cancer treatment, especially when they are taking steroids.

### > TIPS

- Make sure your child eats smaller portions and plan their meals around vegetables, fruit, whole grains and legumes like beans. These are low in calories and high in fibre so they help them feel full.
- Try to limit salty foods. Salt causes the body to hold on to (retain) water.
- Use low-fat cooking methods like boiling or steaming rather than frying.
- Cut back on butter, margarine, mayonnaise and salad dressing. These have a lot of calories from fat.
- Choose lower-fat milk and dairy products, such as skim, 1% or 2% milk or yogurt with less than 3% milk fat (MF). Choose hard cheeses with less than 20% MF.
- Don't skip meals. This may cause your child to overeat later.
- Encourage your child to be more physically active if they can.

It's hard for children to eat healthy foods when the rest of the family doesn't. Make healthy eating a goal for the whole family. Be as active as possible together. Healthy food and physical activity will help your child maintain a healthy weight and keep their bones and muscles strong.

## Weight loss

Some children lose weight during cancer treatment because they find it hard to eat enough. They may lose their appetite or feel like eating has become a chore. At times like this, it's important to find ways to get calories and protein into their diet.

Sometimes it helps to change the way they eat. If they're used to eating large meals, try smaller amounts more often during the day. Snacking is a good way to get the calories and nutrients their body needs. Healthy snacks – like cut-up vegetables or fruit, yogurt, nuts and dried fruits – can also boost energy between meals.

### > TIPS

- Have your child eat small amounts every 1 to 2 hours. Stock your cupboards with quick, easy snacks that they can eat any time.
- Have high-calorie, high-protein snacks prepared ahead of time so that you can serve them immediately if your child asks. A snack should include food from at least 2 food groups. Try cheese and crackers, grapes and cheese, granola and yogurt, yogurt and fruit, hummus and pita, cottage cheese and fruit, veggies and crackers, or a peanut or other nut butter sandwich.
- Make drinks count. Offer higher-fat milk (such as whole milk), milkshakes, soups and juices instead of low-calorie drinks like water, clear broth, tea or diet pop. Offer water between meals so that your child will feel less full and more ready to eat healthy food at mealtimes. Use an infant formula if your child still takes a bottle.
- Choose higher-fat meats such as dark chicken, regular ground beef, wings or ribs.
- Add extra calories and protein to drinks, cereals, baked goods, soups, salads, and main course dishes.
- Make eating fun and interesting. Try serving different coloured foods, use garnishes or try new seasonings. Cut sandwiches and pancakes into shapes using large cookie cutters.

- Include your child in planning and preparing meals if they feel well enough.
- Don't force your child to eat. Try to find a food they will like, or talk about planning a meal or snack for when they feel better.



The nurses gave us big oral syringes and we were able to get her to take yogurt or soup – one dose at a time.

### **When your child can't eat enough**

If your child is losing too much weight, talk to a registered dietitian or your doctor about nutritional supplements or other ways to improve your child's nutrition and weight.

#### *Commercial nutrition products*

Commercial nutrition products are rich in calories, protein, vitamins and minerals. They are available at most pharmacies and grocery stores in the form of drinks, puddings, powders and bars. They can help give your child nutrients when it's hard for them to get enough to eat.

#### *Feeding tubes*

If your child cannot get the calories and nutrients they need by eating and drinking, then the healthcare team, including your registered dietitian, can suggest ways to deliver nutrition through a tube directly to the stomach or intestine. Sometimes a liquid mixture of nutrients is given by intravenous (IV) directly into the bloodstream.



#### **Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) for more information on side effects and how to manage them.

# Staying in the hospital



Children often need to be in the hospital for treatment soon after they are diagnosed with cancer. They also spend time at the hospital for tests and surgeries or to manage side effects. Some hospital stays last only a few days, while others may last for several months.



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

## Helping your child cope

Being in the hospital can be scary for children, especially at first. They have to meet lots of new people and learn about strange machines, tests, procedures and routines. It's a whole new world, but there are many ways that you can help your child cope.

### *Help the healthcare team get to know your child*

When you arrive at the hospital, you can help make things easier for your child by telling the healthcare team about:

- your child's normal routines, likes and dislikes for eating, sleeping and bathing
- your child's special fears, such as fear of the dark, loud noises or needles
- words your child uses to name body parts, important objects or needs that the healthcare team might need to know
- aids such as glasses or a hearing aid that your child uses
- how you would like to be involved in your child's care, such as bathing, changing diapers or feeding



They do rounds every morning. Everybody is there, from the nutritionist to the oncologist to, you know, everybody. So if you have any questions or concerns they're there to help and it's great and they're really helpful. So I was there for that.

## *Try to make the hospital feel like home*

Children of any age will feel more comfortable if you try to create a sense of normal life in the busy, noisy hospital. Of course it's not quite the same, but you can:

- Keep the same daily routines for eating, sleeping and bathing. (You may need to talk to your nurses so you can coordinate these routines with daily rounds.)
- Bring things from home such as your child's pillows, blanket and a much-loved stuffed toy. Bring a few favourite toys, books or games.
- Decorate the hospital room with family pictures and photos of home or your child's room.
- Ask if you can have a regular "family night" in your child's room. Some families have a regular pizza or movie night during long hospital stays. This weekly event helps brothers and sisters feel better as well.

Just like at home, you'll need to set clear, consistent, age-appropriate expectations about how your child behaves. Children find comfort in routine and clear expectations. Of course you can be flexible when your child feels ill or in pain. It's important to respect and respond to how your child is feeling. But children expect and need adults to set these rules, even when they're ill. If there are no rules or if rules change a lot, children may worry that their cancer is worse than they have been told or that they are going to die. It may also be more difficult to re-establish rules later on.

## *Offer choices*

Even in the hospital, there will be many times when you can offer your child a choice. Whether it's about red or blue pajamas, an apple or orange for a snack, playing charades or Simon Says, having a choice helps children feel more in control and less frightened.

Children of all ages will often cooperate more easily if they are allowed to make choices that do not cause problems with their

treatment or care. For example, you might ask which arm to use for blood pressure today or whether they would like the nurse to count down before the needle this time. You can also connect making a choice with having a job to do. They could be in charge of holding the bandages or putting the sticker with their name on it on the blood vial. This can work well with younger children.

“ 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. There were small things sometimes, but they helped him feel involved in the decision-making process. Today, my son’s principal tells me she’s never met such a diplomatic child.

Choose your words carefully, and do not offer your child a choice when there is none. Joanne spent long periods of time in the hospital when her daughter, Abby, was being treated. This approach worked for her. Joanne explains, “The things that she can control, I try to give her a choice on. When she’s getting blood work, she knows she’s getting a finger poke, there’s no 2 ways about it. But I’ll let her choose which finger. And that helps her cope with it. She usually doesn’t cry anymore. She knows it’s going to hurt but she just braces herself and then she smiles while the blood’s being taken.”

### *Meet other children going through similar things*

Just as you probably find it helpful to connect with other parents, kids find it helpful to connect with others who are going through similar things. Many hospitals have playrooms or special programs that allow children to meet other kids who are also in hospital. Some even have outdoor spaces for kids. There may be programs especially for teens such as drop-ins, movies, games or events. Your child may not always be able to join in, but try to take advantage of this when possible.

## Eating at the hospital

In hospital, all meals and snacks are provided for your child. Talk to someone on the healthcare team if your child has allergies, special likes or dislikes, or if your family follows a vegetarian diet or has cultural or religious needs. Most hospitals can adjust the menu for your child.

### *What about food for you?*

Hospitals do not provide meals for family members, but some centres offer:

- some free snacks like juice, yogurt, popsicles, breads and cereals
- meal trays brought to the patient rooms for an extra cost
- kitchens with refrigerators, microwaves and toasters for families to use to store and reheat food from home
- cafeterias or other food outlets in the building

Your child's healthcare team and other families staying at the hospital will be able to tell you more. Find out whether you can bring food from home. Ask about the rules for storing food and using the refrigerators, kettles, toasters and microwaves.

“ We have a good network of friends. And when people asked us, 'What can we do to help? Money?' The biggest thing we said is, 'When you're making some food, make some extra and give it to us so we don't have to cook.' Being at the hospital, one thing they don't tell you is, they provide the meals for your kid but you don't get any meals. So that got costly. Yes there were facilities to cook but you don't have the time. So eating out – that got costly.

## Taking care of yourself

If there is one good thing about being in the hospital, it's that it can be reassuring to know your child is being well looked after by professionals. But the list of stressful things about being in hospital is long. You have to cope with being away from home and family, and you worry about how they're coping without you. Staying in the hospital makes it even harder to balance working and running a household.

It's very hard to do, but other parents who have also spent time in the hospital emphasize that it's important to look after yourself.

“ 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.

### *Take breaks*

If possible, get out of the hospital for at least short breaks. Take turns being there with your spouse or a good friend or family member. Not only will this give you and your child a break from each other's company, it allows other people close to your child to offer their support.

“ What people need is someone to sit there sometimes. Someone to bring them a cup of coffee. Someone to maybe stay overnight, to add a bit of relief. Go somewhere, do something, relax.

If you don't have anyone to take turns with, a hospital volunteer may be able to give you a short break.

“ They come in and offer volunteers so you can get a break from the room and your kid can have a bit of fun. So there's support and there's lot of information available for you there if you want it.

### *Try to get some sleep*

Things usually look better in the morning – if you've had 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 mattress with an electric pump and comfortable pillows. It was always packed and ready to go in our hospital kit.

### *Make the time work for you*

A lot of the time, being in hospital is just boring. Bring a book, puzzles or something to do when your child doesn't need your attention.

You could use the time to keep track of what's happening. Write down the names of your healthcare team, and make notes about important conversations, your child's treatments, tests, side effects or special instructions. Many hospitals provide family journals, binders or even apps to help you stay organized. Update them.

“ 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.

## *Find out what is available to you*

Find out what is available at the hospital and what else is in the neighbourhood. Talk to other parents and staff in the hospital. Ask about gym facilities, parks, restaurants, laundromats and grocery stores. Some businesses and services offer discounts or special passes to patients' families. Ask other parents if they have good tips to share.



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.



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.

## Hospital kit

You may have to go to the hospital without having much time to prepare. Have a hospital kit packed and ready to go. Don't forget to label everything clearly.

*"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 ... whatever 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."*

### ***Need to have in kit***

- your child's provincial health card
- your child's hospital ID card (if your child has one from a previous visit)
- medical information like immunization records and information about drug reactions or food allergies
- medication calendar or list of any medicines that your child is taking, along with how much is taken (dose) and when (schedule)
- medical aids like braces, corrective shoes, crutches, glasses or hearing aids
- disposable diapers or pull-ups for babies and toddlers
- 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
- if you are separated or divorced, any legal papers that show who has custody of your child and who can make decisions about your child's care

### ***Nice to have in kit***

- comfortable clothes for everyday wear, for you and your child
- pajamas, bathrobe and slippers
- toiletries like toothbrush, toothpaste, shampoo, comb or brush
- pillows and blankets from home for you and your child
- a few favourite games, toys, books or family pictures that are important to your child
- school books and current school work
- 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

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



# School



Children often have to miss school while they're being treated for cancer. And sometimes they have to miss it for long periods of time.

## Missing school

Yvonne's son, Zachary, was diagnosed with Hodgkin lymphoma in the first term of grade 8, his final year at his school. Zachary, who has high-functioning autism, was looking forward to a great year being "king of the school." He had friends, and he was ready to work hard and then move on to high school. Instead he missed much of the year after urgent surgery and spent long periods of time in the hospital. His cancer experience left him "isolated" and with "nothing in common with his friends."

On the more positive side, Zachary kept up with key subjects thanks to a great teacher on staff at his treatment centre. She worked with him, then graded him, and he graduated with his class at the ceremony at the end of the year. For Yvonne, a teacher herself, it was "really touching - when he went up to get his diploma, he had a standing ovation."

Missing school for weeks or months is hard on kids because they get behind on their subjects and they miss their friends or feel isolated and different from their peers. Encourage your child to go to school when they can. But when missing school is necessary, these strategies can help.

### *Ask about teaching support at the hospital*

Depending on the size of the treatment centre, there may be a hospital school teacher who can work with the teacher at your child's school to make sure your child continues learning as much as possible during treatment.

### *Work with your child's school*

Talk with people at the school and hospital to make a plan that meets your child's educational needs both during and after treatment. Your child's doctors may be able to guide you on how treatment may affect your child's ability to be at school or keep up with schoolwork. Ask the school about what schoolwork your child will miss and ways for your child to keep up, as they are able. If your child is well enough to keep up with some work at home, ask the teacher to send work home.

Teachers can encourage classmates to keep in touch with your child by sending letters, pictures and emails or connecting by social media.

Make sure the school knows that being exposed to typical childhood diseases or sicknesses can be very serious for a child with cancer or recovering from cancer. Ask the school to let other parents know that they should tell the teacher if one of your child's classmates develops a disease like chickenpox, measles or shingles.

### *Consider private tutoring*

A tutor can help if your child is going to be away from school for some time. If your child has kept up with their studies, it can make it easier for them to go back when they are feeling better. But hiring a tutor can be expensive at a time when you can't afford it.

### *Help friends and classmates understand what your child is going through*

Give them some basic information about cancer and cancer treatment. Tell your child if they will look different during or after treatment. Tell them how some treatments can cause changes in mood or behaviour. A teacher or a member of the healthcare team may be able to talk to your child's schoolmates.

“ We had the liaison nurse come and talk to my daughter’s class so that they had the right information. A letter was also sent home to the parents of these kids to raise awareness and educate.

## Going back to school

For many children, going back to school is a welcome sign that life is returning to normal. It’s good to get back to a routine and to be around other kids.

That doesn’t mean it’s easy. Some children are very behind in their grade and are worried about it. They may have very little energy to help them study and get caught up. Friendships may have changed. Children may be anxious about going back because they look different. They may worry about being teased and not fitting in.

“ 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.

## *What you can do to help*

When Alana’s son, Cole, returned to school after treatment for medulloblastoma, he found school tasks like printing were very hard because his fine motor skills were affected. Alana sat down with school staff and they worked out ways for Cole to continue learning and then to be evaluated. “We sat down and we brainstormed. We decided he would use a laptop in the classroom and that he would type all of his assignments instead of writing them out. Because all that really matters is he can spell and he can compose a sentence. So we just try to come up with ways to adjust.”

Continuing to talk regularly with teachers and other staff at school is a key part of helping your child adjust to being back in the classroom. Younger children especially need you to speak for them and their needs. Along with talking to the school about ways Cole could continue learning, Alana turned to them when Cole started at a new school and was bullied. “My son is now so much smaller than other kids his age. He’s the size of a 5-year-old in a class of 10- and 11-year-olds ... the other kids gave him a hard time. With help we got it sorted out quickly. A mental health worker went to talk to his classroom with the message that making fun of people’s difficulties is the same as bullying. And it seems to have helped.”

If this hasn’t happened already, you can ask someone from your healthcare team, a nurse or social worker, to talk to your child’s class. Encourage the children to ask questions to clear up misunderstandings. You can also:

- Start with short visits and increase school work gradually. Many children have very low energy after treatment.
- Invite a couple of classmates home to visit your child before returning to school. Consider asking them to be a “buddy” so that your child has friends at recess or in the lunchroom.
- Ask older children and teenagers how much information they’d like to share with their classmates. Then help them share it.

## New challenges in learning

Most children are able to catch up with the school work they missed. It may be hard at first, especially if they're still tired or feeling sick from cancer treatment. For some children, the kind of cancer and cancer treatment they had may affect their memory and ability to learn. Sometimes, these troubles show up as a late effect long after treatment ends.

“ My son found returning to school very difficult. He had learning disabilities 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 a feeling of success and to feel good about himself. He absolutely prefers it.

If you think your child is having trouble learning, talk to your child's teachers, school psychologist or special education consultants. Talk to your healthcare team. Your doctor or psychologist might recommend a psychoeducational assessment to identify your child's weaknesses and strengths. This assessment can be shared with the school to plan extra supports for your child.

# Coping within the family



When a child is diagnosed with cancer, life changes for the whole family. You will all react in your own way. It's normal to feel afraid, angry, sad, guilty or out of control at times. The whole family must try to cope with these strong feelings while caring for the child with cancer and also keeping up with everyday activities and responsibilities.

## How parents can cope

When a child is sick, parents naturally feel they must do everything possible to help that child get well. But you're only human. Be realistic about what to expect of yourself. You're allowed to feel the way you feel, and you don't have to hide it. It's healthy to express those feelings as you go along. Give yourself time to feel them.

“ It's OK to just sit in the bathroom and just cry your eyes out. And it's OK to just say to yourself, it's your fault, but you know it's not. And that if you need to take 10 minutes and go for a walk with no one at all, don't feel guilty about it.

## Take care of yourself

Taking care of yourself isn't selfish. If you don't take care of yourself first, it will be harder to take care of your child and your family.

- 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 as much as you can. Try to eat and sleep well, deal with any of your own health problems, be active when possible and take regular breaks from looking after your child.
- If possible, take turns with your spouse or another support person when you are staying with your child in the hospital or going to other appointments.

“ I had my girlfriend come up for 2 weeks just so I could have a break - walk out of the hospital, not have beeping machines and not see [my daughter] lying in the bed. You need a little bit of a mental break and usually that only comes with when

you have friends or family, someone that you trust who can stay with your child. You know if anything were to happen they're not going to lose their cool, they'll take care of things.

- **Socialize.** It's tempting to avoid seeing friends while you're feeling unhappy. But do your best to keep up with your usual interests. Doing so will bring a little bit of normal to your life.

“ 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.

### *Get support from others*

Talk to people you know – your spouse, partner, close friends and relatives – about your feelings, fears, concerns and hopes for your child. If you prefer to get support from someone who isn't so close to you, ask someone on the healthcare team. 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 spiritual care worker. You can also get support by expressing your feelings in letters or a blog.

Many parents find it helpful to talk to other parents of children who have cancer. Some parents prefer to get their support from outside the cancer community, and that's OK too. Other parents of children with cancer may have ideas about how to cope or they may tell you about useful resources. Try a support group if there is one in your area. Consider joining an online community. Whether you meet face to face or online, these groups are a place for families to share their experiences. Parents say they give them a safe place to vent, learn, laugh and cry.

“ You get to talk to people going through similar things, which is very important because they can understand you. They know what you're talking about. They've gone through similar situations. If not the same diagnosis, their child is still

in the hospital. They know about different procedures, things a regular person just wouldn't know about... You get a chance to discuss that and learn what might work and what else you can try for certain situations. They don't necessarily tell you in the hospital.

### **Talking to someone who's been there**

If you would like to talk to another parent whose child has had cancer, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at [match.cancer.ca](http://match.cancer.ca) or call us at 1-888-939-3333.

### **Want to connect with someone online?**

If you'd like to join our online community, visit [CancerConnection.ca](http://CancerConnection.ca). You can read news, join discussion groups that interest you, get support and help others at the same time. You'll find caring, supportive people there.

### ***Take care of your relationship with your spouse or partner***

The stress of caring for a sick child can cause friction in a relationship. It's very important to make time to talk to each other. Try to share your feelings honestly and openly. Sharing feelings and information helps you stay connected and can help you to make decisions about your child's care.

Find private times to be together. Talk about something other than cancer. For Alana and her husband, time spent in the hospital turned out to be time they could spend together. "For a lot of the stuff, we weren't allowed in. For his radiation, we couldn't be there. It took an hour. For his MRIs, that was almost 2 hours, and we weren't allowed to be there. That was when we would sit and we'd decompress and we'd just talk about anything but what we were doing right now."

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

Do your best to respect the different ways each partner copes. Parents often deal with stress in different ways. In Joanne's case, she recognized that her partner found their daughter's cancer experience extra stressful. He had had the same type of cancer as a child, and it brought back a lot of unpleasant memories that he also needed to cope with. "So his way of dealing with it is to kind of stay out of the picture. He wants to be the one to go to work. Work helps him cope."

There is no right or wrong way to cope – just different ways. Some people find talking helpful, some want lots of information and some want to withdraw. Try to understand and be sympathetic to your partner.

“ We've been together forever. We tried really hard to not let any of this affect me and him. I knew how hard it was for me, I saw how hard it was for him. He was under a lot of stress. He had to start taking medications. I completely understood. And you just support each other. That's all you can do.

You may have to find new ways to share responsibilities in order to care for your sick child and keep things going at home. Any kind of change can cause stress. Talking about these changes with your partner can help you learn to accept them. In some families, one parent may give up a job or work less than the other. These role changes may be for a short time or they may become permanent.

### **Terry's story – How roles can change during treatment**

A few days before his daughter Isabella's first birthday, Terry got a call to rush her to the hospital after blood tests showed a very high white blood cell count. Later that night they were told Isabella had acute myelogenous leukemia. It took a bit of time for it to sink in that the treatment would last about 6 months and either Terry or his partner, Jocelyne, should expect to be at the hospital full time.

They decided together that it made the most sense for Jocelyne to stop operating her home daycare and be at the hospital. Things got complicated quickly. Terry had recently torn apart their basement to renovate it. That big

project was put on hold, but then they found out that Isabella wouldn't be able to come home until the walls were closed up. After a month of trying to juggle everything, Terry had to take time off work. "I was on EI, Jocelyne wasn't working and I was trying to get a renovation done so my daughter could come back home. It was a very trying time."

When the treatment finally ended, they took Isabella home and began to rebuild their lives. Terry went back to work and Jocelyne re-opened the home daycare.

Eleven months later, the cancer was back. As plans were made for Isabella to go back in hospital for a bone marrow transplant, Terry said to Jocelyne, "This time it's me." He wanted the experience of being there for his daughter, and Jocelyne's business was thriving. But even though he's "kind of on the cusp of old school and new school," Terry grappled with deeply ingrained attitudes about men and their role and felt those pressures. "You're the man. You need to keep your stuff together. You need to go to work and you need to provide for your family."

Terry regrets nothing about his decision, but he admits it was a really tough time. They were isolated in a "clean" room to protect Isabella from germs, and there were days when it felt like a prison. He'd been told what to expect for Isabella, but he had no idea how he was supposed to react and he often wasn't sure how to cope. Even so, there was a bright side: "As crappy a time as it is, when I was in the room with Bella, I had 6 months of undivided time with her so I got to develop a pretty good bond with her."

The transplant went very well. Today, Terry and Jocelyne have a new appreciation for life. They now have 3 children, Jocelyne has a flourishing home daycare, and Isabella has started school. "Everything she does for the first time, it's a little like, wow, we didn't know if we were ever going to see this. So it adds a bit of extra importance to it." They're thinking of moving closer to family after all they've been through. It will mean more people to help Isabella celebrate both her birthdays. Terry explains: "She gets 2 birthdays now. She gets her real birthday when she was born and she gets her 2nd birthday for her second chance at life."

## *Find easier ways to communicate information*

Keeping everyone up to date on how your child is doing can be stressful and time consuming. And sometimes, you just don't want to talk.

Some parents choose a family member or friend to act as a spokesperson and help share any news. How much you share is up to you, so you'll need to talk that over with your spokesperson. If it's hard to keep up with phone calls, you can leave a recorded message on your phone thanking callers and directing them to the family spokesperson.

Sending out a regular group email or updating a family web page or blog are also efficient ways to share news.

“ We had about 200 followers for a group for [our daughter] that we would update on a semi-daily basis to keep everyone in the loop as to what was going on. And that way we didn't always have to answer questions.

## *Let family and friends help you*

You're not alone if you find it really hard to ask for or accept help. But parents who have been where you are right now will tell you that you need help of all kinds – emotional, practical and financial – to get through this experience.

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

“ 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.

“ 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.

If people ask what they can do to help, tell them. You may need help looking after a pet or your property. Perhaps you could use some help around the house or watering plants while you’re away. Friends might be very happy to give you a break at the hospital if you ask.

“ Parents should be more honest about what they need. Throw social niceties to the wind. People will say, whatever you need just call me. Well, what can I call you for? Can you come and clean my house? Can you bring food to the house? If there are other siblings – can you babysit? Can you walk my dog? What can I count on you for? Actually get a commitment from people. Because a lot of people want to help but they don’t know what to say. So if you actually give them something concrete, they actually like that. I had one friend who said, ‘If you’re on the GO train, I don’t care what time it is. Call me and I’ll pick you up.’ She did.

Most families find any help with groceries and meals to be very useful.

“ 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.

## Choose a point person

Even if you've accepted the idea that you need help, you may not have the time or energy to figure out what you need, let alone the time to organize it all. You might find it helpful to choose a point person to organize things for you. If you do feel awkward about asking for and accepting help, this set-up may really work for you.

If you know what you need, a point person may be able to work from a list that you provide. Or choose a point person who knows your family well enough to know what you need without being told.

Your point person might find it helpful to go online and search for "helping calendars" or "free online meal calendars." These allow meals, chores or visits to be planned and tracked.

If you are open to it, you may be amazed at the creative and individual ways that people will try to help you and your child.



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.

## *Single parents and blended families*

There are many kinds of families today. Single-parent families and blended families are common.

### > **TIPS**

- Tell the healthcare team about custody and access arrangements. They need to know who is allowed to make decisions about your child's care.
- Set up a plan to make sure both parents (if applicable) receive the same information even if you cannot attend meetings together. Ask for 2 copies of materials and treatment plans. Talk about how you will share important health information if your child goes back and forth between different homes.
- Come up with a plan to make sure that medicines are given when they should be. You don't want them given twice or not at all. Having one medicine calendar that stays with the child can help.
- Ask about volunteer programs at the hospital – and then use them.
- If your relationship with your ex is difficult, ask your social worker or psychologist for help. They may be able to help you cope with strong feelings. They may also be able to help you and your ex work together to help your child.

## Yvonne's story – Asking for help

When Yvonne's 13-year-old son, Zachary, was diagnosed with lymphoma, "Everything that happened was outside the box. Things were supposed to go a certain way and nothing went the way it was supposed to go." As a single parent who worked full time as a teacher, Yvonne had to balance everything and find ways to support herself and her son.

She spent long days caring for Zachary and worked every night writing lesson plans for the supply teacher who was taking over her classes. Very soon, she was exhausted and depressed. She decided to take a leave from school when the term ended.

As a teacher, she had good benefits – sick leave, disability insurance and a drug plan. But as a single parent she had used a lot of her leave for other illnesses. She also found that the drug plan required that she first pay for medicines and then submit receipts to have the costs reimbursed. One of the prescriptions cost thousands of dollars a month. She had very little savings and was living from cheque to cheque.

Zachary had a terrible time with the treatment. He became very anxious and depressed. To make things even harder, he has high-functioning autism. "He was very quiet, his face would show no emotion so they took that as he was fine. But really he was locked in a prison he couldn't get out of. He was so sick and so anxious and feeling so terrible he couldn't express himself."

Yvonne learned to ask for help. A neighbour fed her cats while Yvonne spent long periods of time at the hospital. A friend helped her out with rides when needed. A social worker signed her up for benefits from a community organization, filed gas claims for her car and even wrote a letter to have her phone bill reduced. Yvonne did her own research, too, picking up brochures and following up if someone suggested a place to look for help. Her union helped her arrange a leave. She found out about a disability tax credit and other income supports when her leave ended.

The biggest challenge was finding help for her son. When his treatment finally ended, he was still suffering from late effects that affected his mental health. Again, Yvonne asked for help. She found a psychiatrist at the hospital, a treatment program in the community and a residential mental health program. Zachary still has issues with anxiety and depression, but things are getting better. "It's really hard to get a hold of mental health problems once it gets so far. If we'd had more help, I don't think it would have gone as far as it did."

Even though her experience was very difficult, Yvonne urges other parents to reach out for help when they need it. "I'm telling you to try. People will help more than you think they will."

## Helping brothers and sisters cope

Brothers and sisters of children with cancer must deal with lots of changes and disruptions to their routines. They miss you and their sibling when you're at the hospital and they have to cope on their own more often. They often have lots of strong feelings about the changes that cancer brings. They may feel:

- worried about their brother or sister
- upset that their parents have less time for them
- angry, jealous or left out because of all the attention the sick sibling is getting from parents, friends and other family members
- guilty that they are healthy when their sibling is not
- guilty about feeling angry or jealous
- afraid they did something to cause the cancer or afraid they or their parents will get sick too
- sad, lonely or isolated because no one understands what life is like for them

Brothers and sisters may not want to tell you about strong, negative feelings they have. Sometimes kids hide how they're feeling by trying to be the perfect child. Some children act out their feelings. They may develop headaches and stomach aches or have trouble sleeping or have trouble in school.

In Joanne's case, the family knew that there was a chance that new baby Abigail would have retinoblastoma. What was a total surprise was the challenges they've had with their son, Alexander. "I think our biggest challenge overall is not even with her, it's with our son. He was 3 when she was born and his life just got turned upside down. Here he's supposed to have a little sister coming home with Mom, and we're gone for long periods of time." Alexander could visit his sister in hospital only a little bit because treatment for Abby was far from home. The separations have been hard. "It feels like they're constantly working on their relationship. They finally get to a place where they're happy and they play nice, and then they're separated and learn to do it over and over again."

Children don't always know how to talk about their feelings in words. Alexander didn't for a long time, but he is starting to now. But at first, he acted out his frustration over the situation and the attention his sister was getting. He kept his feelings in, and then would explode, taking it out on other children and the family. Joanne explains, "In a way, it's kind of, any attention is better, whether it's good or bad." This also made things extremely challenging for Joanne and her partner. "When we are together he tries to play us off one another. He knows I feel guilty about being away, so I tend to give in more than Daddy does."

The strategies in helping brothers and sisters cope are similar to helping the child with cancer.

### *Talk about cancer*

Be honest and direct. Depending on their age and understanding, brothers and sisters need to know as much about the diagnosis, treatment and side effects as the child with cancer.

“ We used the child life specialist and the liaison nurse at the hospital to help us with ideas for the right language to use when explaining leukemia to our 6-year-old and then adjusting that language for our other 3 kids. We were very open with everything but at an age-appropriate level. My daughter's cancer is often a weekly topic of discussion as the kids process things and as we as parents go through the steps of swallowing what living with cancer means.

Kids use their own logic to try to make sense of what's going on in their world. Along with giving them information they can understand, you also might need to correct some of the things that they've connected in their own minds. Let them know that cancer is not contagious. They need to understand that nothing they did caused it.



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 give their kids as much information as they can handle because they're thinking about it, even if they don't say much.

You might need to prepare your children for changes in how their sibling looks. Cancer treatment can cause changes such as hair loss, weight gain or weight loss. Some treatments can cause changes in mood or behaviour. These changes can be frightening for brothers and sisters.

### *Talk about their feelings*

Let them know that strong feelings are normal. As a parent, it can be hard to sympathize with healthy siblings. Given everything that the family is going through, you want them to be helpful and understanding. But brothers and sisters are not meant to be little parents to their sick sibling. It's healthy for brothers and sisters to worry about their own needs. Once you find out what their needs are, you can figure out what to do about them.

Help them learn the difference between having feelings and acting them out in ways that hurt themselves or others. Show them different ways to release and express strong feelings through physical activities like running or sports and through art, music or talking.

## *Talk about home life*

When a child has cancer, a family's routines quickly change. Some parents find it helpful to have family meetings to talk about the schedule for the week. As much as you can, tell your children what's happening each day - who will be home, who is at the hospital and who will be looking after them. A calendar with pictures to show who will be at home and when can help young children understand the plan.

Try to keep routines as consistent as possible. Many families say that keeping some routines going helped them cope during a difficult time. When you can't keep to a routine, try to give your child a choice. Perhaps your child can decide where to go after school or who to stay with if you are at the hospital.

“ 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.

Expect your children to follow your family's usual rules of behaviour. Let them know that the child with cancer is expected to follow the rules too. There may be times for everyone when you have to be flexible, but being consistent will help all your children feel that life is more normal.

## *Get them involved*

Let your other children come to appointments to see for themselves what they are like. Let them visit their sick sibling in the hospital. They can get to know the staff, ask questions and spend time with their brother or sister. If they don't want to, take the time to talk about it. They might be scared of what they'll see. Even if you have to travel for treatment, it may be possible to take siblings along. Your social worker may be able to help find somewhere the family can stay or tutoring for siblings if they have to miss school.

“ When she's through with the isolation part, she still has to stay in the hospital but she goes into a step-down room. She's allowed to leave the room and she still has to stay on that floor. But they have a family lounge where she can go and see visitors. We hope that once she's allowed to do that, we can bring her brother down. She'll be happy to see him and he'll be happy to see her.

“ He keeps saying when he grows up he wants to be a researcher so he can make potions that can cure cancer. You don't hear that coming out of a 6-year-old very often.

You can also explain that things like proper handwashing help their sibling. They can help the whole family out with jobs like setting the table or feeding pets.

## *Help your child feel loved and listened to*

This one is very challenging, because your sick child needs so much of your time. Siblings normally find it comforting to hear that you love them and that you understand that things are also hard for them.

Try to spend some special time with your other children, doing things that they enjoy - reading stories, playing in the park, going to the movies or going out for dinner. This will help them feel that you love and care about them even when they get less attention than usual. If you can, spend a short amount of time together every day - even 10 minutes can help.

Sometimes families of children with cancer are given tickets to events in the community. These can be great for a brother or sister, not just the child with cancer.

“ 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.

When your attention must be elsewhere, this can be an opportunity for siblings to form strong relationships with other important people in their lives. Alana and her husband found this worked well when they had to spend periods of time at the hospital, which was far from home. “We always made our trips to Halifax as special trips for them to go to Grannie’s house. Grannie would spoil them rotten while they were there and they would have fun.” Not only did the kids have a great time and get to know their grandmother very well, but knowing that the other children were so well cared for helped Alana focus on Cole.

For older kids especially, keeping up with favourite activities and lessons is important. If other family members or close friends can spend this time with them, everyone will benefit.

### *Tell caregivers and teachers about the cancer diagnosis*

Children may show their feelings about what's happening at home by changing the way they act at school or daycare. If school or daycare staff know about the stresses your family is facing, they can help. They may be able to offer extra support, counselling or help with school work.

### *Ask about programs for siblings*

Your hospital social worker, psychologist, child life specialist and art therapist can help with siblings' issues. You may want to talk to the counsellor yourself or set up an appointment for your child. Counsellors may be able to recommend community or hospital programs especially for siblings of children with cancer.



#### **Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) for age-specific ideas on helping siblings cope.

## Getting help from the healthcare team

Getting through cancer treatment isn't easy, but families can cope if they have enough support. For some family members, this may mean getting support from a healthcare professional, not just family and friends. And that's OK. It's a sign of great strength to ask for this type of help for yourself or for someone you love. It also shows the child with cancer that it's OK to ask 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.

### *Stress and anxiety*

Symptoms of stress and anxiety include excessive worrying, tense muscles, trouble sleeping or getting too much sleep and feeling restless. Your heart may race, you may tremble or feel short of breath, with tightness in your chest, or have nausea, dizziness or high blood pressure. When you are stressed and anxious it is hard to concentrate and you may be irritable and impatient.

Being stressed or anxious is a very common response to a cancer diagnosis. For some, the symptoms of stress and anxiety can be severe, making it hard to cope with daily life. Talk to your doctor or healthcare team if you feel stressed or anxious.

## Depression

Depression is a term that describes a range of emotions and behaviours. Feeling sad is a normal reaction to a cancer diagnosis and to the many changes that happen during treatment. Your child may cry more than usual, your teen may lose interest in their usual activities, you may have headaches or trouble sleeping. These feelings can come and go for anyone in the family during cancer treatment and afterward. They may be a sign of clinical depression if they:

- become worse or last for a long time
- go along with other symptoms such as feeling worthless or guilty, changes in appetite, weight or sleep, having difficulty thinking or having regular thoughts of death or suicide
- start to take over your thoughts or your child's thoughts and affect daily life in a negative way

Depression can and should be treated, in both children and parents. Someone who is clinically depressed can't just "cheer up" using willpower alone. Only a medical doctor, psychologist or psychiatrist can diagnose depression.

If you're worried about how anyone in your family is coping, talk to someone on the healthcare team. They may have recommendations about finding the right resource, community or hospital program. Psychologists, social workers, art therapists, family doctors or psychiatrists can help if your child or teen:

- has more trouble with learning or paying attention
- is often angry or defiant
- no longer seems interested in social activities
- has problems sleeping or eating
- complains a lot about how they feel physically (for example, has stomach aches or headaches)
- starts taking more risks than usual or gets in trouble at school or with the police
- is taking drugs or drinking alcohol
- talks about death often

# Money matters



Cancer can affect your finances. You may take time away from work to be with your child, while at the same time you have extra child care or transportation costs or need to pay for some drugs and therapies that aren't covered by your province or your private health insurance plan. Losing income at the same time as having unexpected expenses leaves many parents worried about their finances.



Money causes so much stress when this happens. It doesn't matter how much money you make. It just goes when your kid is sick.

## Getting answers to questions about money

A social worker at the hospital or treatment centre can help you find financial assistance programs in your province or territory. They can also help you fill in and submit forms.

Many people have private health insurance with their employers or through a private insurance company. Your human resources staff member at work or your private insurance broker can let you know what your plans will cover, such as paid time off or medicines. Be sure to ask:

- what the insurance will pay for
- what you will need to pay for
- will you have to pay first and then be reimbursed
- how to apply to get the coverage you need
- if there are any waiting periods before coverage starts



If he'd worked for anyone else I don't even know what would have happened. They said, don't worry about it. We'll cash out all your vacation and sick days and we'll see what we can do with regards to compassionate care leave and we'll help you do anything we can. They were just amazing.

Account managers at your bank, personal financial planners or advisors can help you budget your money and suggest solutions when finances are tight.

An accountant can tell you about expenses you can claim on your tax return.

### **Stay organized**

Government programs and insurance companies often ask you to complete lots of paperwork. Be prepared so that you don't miss out.

- Keep all of your receipts for medicines, travel, meals out of town and other expenses to submit to your insurer or attach to your tax return.
- Keep track of key dates for submitting applications and receipts so that you don't miss deadlines.
- Make photocopies of any paperwork that you mail.

## **What you might need to pay for**

### *Medicines and equipment*

The Government of Canada gives funding to provinces and territories to pay for all hospital and physician services that are medically necessary, including medicine and treatments used in hospitals. Outside the hospital, you are usually responsible for paying for any medicine your child needs. You may also need to buy equipment or pay for therapies that the government does not cover.

For children, most chemotherapy medicine is given in the hospital. But many children also take medicine outside the hospital as part of their cancer treatment. They might take oral chemotherapy, antibiotics or medicine to control nausea or pain.

“ There’s a medicine for the white blood cell count – it’s really expensive. Of course, that’s given after the chemo, so you’re at home usually. You have to have your own amount at the house and that’s like thousands of dollars for the month. And our drug plan is that you have to pay the money out before you get it reimbursed.

### **The cost of medicines**

Some Canadians can have all or part of the cost of pain medicines covered by private insurance plans, provincial or territorial drug benefit programs, or federal programs for certain groups of people. Each province or territory has different rules.

### ***Transportation and somewhere to stay***

Many families live far away from the centres where their children are treated. So you may have to pay the costs of getting to and from treatment as well as a place to stay. Your provincial government may have a benefit plan that helps pay for these travel costs and where you stay while your child is in treatment. Ask your social worker if you qualify for any of these programs.

“ One time we went in for a PET scan and the machine was broken. So they had us in a hotel room. We just had to go from it to SickKids and we were there for 4 nights. It was nice and the room was paid for, but the problem was I still had to pay for parking and food. So it’s expensive.

## Government financial support

The Government of Canada provides benefit programs (financial support) to people who are sick themselves or to people who are caring for family members who are sick. Talk to your social worker about federal benefit programs, visit the Government of Canada's website at [canada.ca](http://canada.ca) or call 1-800-O-Canada to see what you're eligible to receive.

Most provinces and territories also have benefit programs to help parents of children who have physical or mental disabilities.

“ My daughter had leukemia so she was considered disabled and we were able to get some pension from the provincial government. So that helped. We get a federal child allowance plus a provincial child allowance but it was augmented a bit because our daughter was considered disabled. And another thing that helped was after the bone marrow transplant we were able to get an increase in our allowance from the federal government to help with expenses during that time. That was something we had to dig around and find out for ourselves. I'm lucky that we asked a lot of questions to find that stuff out but otherwise we wouldn't have found out. It's money that we would've missed out on.

You may also be able to claim tax credits on your tax return for your expenses when your child has cancer. To find out more, visit the Canada Revenue Agency at [cra-arc.gc.ca](http://cra-arc.gc.ca).



### Need more info?

Visit [cancer.ca/whenyourchildhascancer](http://cancer.ca/whenyourchildhascancer) to find out more about financial help, including programs that you may be eligible for.

## Community donations

Parents of children with cancer say that money is often a real struggle during treatment, but many are also quick to note that there is community help out there – if you can find it. Many organizations, charities and businesses provide financial support, services and donations to families of children with cancer.

Alana remembers searching for this kind of help when her son, Cole, was in treatment. “I think I just googled ‘assistance when your child has cancer’ and looked at every single thing that came up. It brings up so much stuff too. That’s how we found out about Camp Goodtimes. My son goes to that camp every single year. I think he looks forward to it more than Christmas.” When Abigail was being treated, her mother, Joanne, found it helpful to ask anyone and everyone on her healthcare team for suggestions. “We got a little bit of help from the social worker and we went online looking for anything that we could find. We called everybody. We called our health nurse, our pediatric oncology nurse, we got as much information from her as we could.”

Your social worker may know of some organizations in the community or you can approach places yourself:

- Private businesses like gas stations, grocery stores or coffee shops may offer gift cards.
- Some community organizations provide services such as transportation at low or no cost.
- Family foundations or charities may offer financial support, grants for specific services and in-kind donations of items you might need.
- Cancer organizations that focus on children with cancer may offer you services and support such as children’s camps or transportation to treatment.

## Camps for children with cancer

The Canadian Cancer Society has camps for children with cancer in some provinces. To find out more, email [info@cis.cancer.ca](mailto:info@cis.cancer.ca) or call 1-888-939-3333. For a list of all the accredited oncology camps in the country, visit the Canadian Association of Pediatric Oncology Camps (CAPOC) at [capoc.ca](http://capoc.ca).

“ When you get to the ward they hand you pamphlets. They say if you need this, then talk to these people. The Canadian Cancer Society was one of the ones that was handed to us. POGO helps with meals and accommodation if you need it. The hospital itself has no problem writing you letters to get you a reduced rate at the hotels around town if you don't qualify for Ronald McDonald House. There's a lot of help available out there, but you have to be willing to ask for it. Some people feel bad taking money but it's there to help you. To ease the burden so you don't have to worry about that. You can just worry about your child.

## Fundraising

Friends or family members may offer to hold a fundraiser to help pay for your cancer-related expenses. Some host events, others conduct online campaigns or collect donations in other ways. These efforts can be very helpful but here are some questions to think about before the event:

- How will the money be spent?
- Who will decide how to spend the money?
- How much does my child and my family have to be involved in the fundraiser?
- Does the money raised have to be declared as income on my income tax return?
- How will this income affect me if I am getting other government benefits?

“ 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 they can get.

## When treatment is complete



When treatment ends, you may be surprised to feel happy and relieved but also nervous and scared. Treatment is complete, but what other care will your child need? What will daily life now be? How do you move forward?

“ 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.

## Your child’s treatment summary

When treatment is finished, your healthcare team should give you a summary of your child’s cancer treatment. The summary usually contains information about:

- date of diagnosis and test results
- type of cancer, including the tissue or cell type, stage and grade
- names and doses of all chemotherapy drugs
- parts of the body that received radiation and the radiation dose
- types and dates of any surgeries
- bone marrow, cord blood or stem cell transplants and graft-versus-host disease
- significant complications or side effects and treatments received
- plans for follow-up

Keep this summary somewhere safe. Healthcare professionals who care for and monitor your child in the future will need it. This record will help the doctors and nurses to watch for and manage any late effects of cancer treatment.

“ Right now at SickKids he’s being transferred to a program where he’s being liaised with Princess Margaret. It’s a different doctor but they walk him through and they introduce him to the process there. Knowing them, they’re probably doing an excellent job.

## Follow-up care

An important part of life after treatment is follow-up care. Every child's schedule will be different. The length of follow-up depends on the type of cancer, cancer treatment and side effects. Your nurse or doctor will give you a schedule of appointments and tell you what tests your child will need.

“ I was under the impression that once surgery and chemo were finished, the worst would be behind us. I was scared when chemo was finished, and some do wish chemo could continue so they know it wouldn't come back (This surprised me!). Also, follow-up appointments can be stressful. There is a definite fear of what could be found, both by the parents and the children. Also, I am paranoid of any ache or pain that my daughter has.

### Working with the healthcare team

The main purpose of follow-up care is to make sure that cancer has not returned and to help your child stay as healthy as possible to make the transition to life after cancer. If the cancer does come back, the healthcare team is there to help you. To get the most out of follow-up care, you can:

- Talk to your healthcare team about the chances and signs of the cancer coming back.
- Ask your team what you should do if your child develops a fever or becomes ill. Who should you call? What should you do to manage the illness?
- Ask what your child can do to stay healthy. Are there any activities they should do or should not do? Can they help create a wellness plan for your child?
- Does your child need vaccines? Many children have not kept up with the vaccine schedule during treatment or will need boosters.
- Talk to your healthcare team if you notice that your child is having emotional problems, trouble learning or trouble getting along with friends. Some children may be affected months or years after treatment ends and they finally realize what happened to them.

*“I turned to online forums of parents who were transitioning into after care. I also used our nurse clinician a lot. We were naturally nervous about having the ‘crutch’ of treatment removed and forgot how to live life normally. I’m sure we drove her crazy with questions, but each question that was answered put our minds more and more at ease.”*

## Watching for late effects

The cancer treatment that has saved your child's life may cause health problems years after the treatment has ended. These health problems are called late effects. Having long-term follow-up care means the healthcare team can catch late effects early and start taking care of them right away.

“ Everything's really good with her now. We have some minor issues we're working through. Just behavioural issues. We don't know if it's just something normal or if it's something as a result of the treatment. So we're working closely with the neuropsychologist. Just to see if we're being overbearing and overprotective or if there is something that's going on.

The risk of late effects depends on many things, including the type of treatment, the amount of treatment, the child's age at diagnosis, genetic factors or other health problems the child had before cancer. Talk to your child's doctor about what they will watch for in the years to come. The reason that follow-up goes on for many years is to manage any late effects. It is not because the healthcare team thinks the cancer your child had will come back. Late effects include heart or lung problems, growth and development issues, learning difficulties and sexual development and fertility issues. For a very small number of children, being treated for cancer as a child increases the risk of developing a second cancer later in life.

“ I broke down twice during the entire treatment. Once when I found out my daughter had leukemia – the second over the stupidest thing. When we were told she would have to go in for the bone marrow transplant, the doctor said she was probably going to be infertile. For me, that's where I got really upset. Even now, it's tough. You see her walking around carrying babies and talking about having her own children. Not that having your own children is what makes you a mom, there's lots of other ways to be a mom. But those were the only 2 times where I got upset.



### **Need more info?**

Visit [cancer.ca/whenyourchildhascancer](https://cancer.ca/whenyourchildhascancer) for more information on late effects.

## **What's your new normal?**

Many families wonder how to put their cancer experience behind them and return to normal life. Everyone in the family will deal with what has happened in their own way. This can cause tension that you weren't expecting. But there's no perfect way to move ahead - you'll need to figure out what works for you and your family. It will take time to get to what survivors often call a "new normal." Creating your new normal at home, work and school could mean thinking about:

- how to support your child's return to school after lots of time away
- finding a balance between protecting your child and letting them try things on their own (the healthcare team can tell you if there is anything your child shouldn't do and for how long)
- adjusting the roles, routines and responsibilities of all family members now that you are not spending so much time in the hospital or clinic
- when and how quickly you should go back to work and how you will rebuild relationships with co-workers
- rebuilding your relationships with your spouse and close friends
- connecting with people who can help you sort out your concerns, feelings and questions about everything that happened - friends, family members or other families who understand your experiences.



At the end of treatment, you're all finished, you get this 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.

### **Do you want to celebrate?**

Some families mark the end of treatment by celebrating in some way. You might:

- Take goodbye pictures of the hospital and staff.
- Give trophies, medals or small gifts to your child and their siblings.
- Ask the cancer centre to give your child a certificate or special card from the staff.
- Ask friends and family members to send congratulations cards to your child.
- Have a party.
- Have a special outing or vacation.

### **Alana's story – Learning as you go**

Alana's new normal has been one big question mark since her son, Cole, was treated for medulloblastoma. The surgery to cure Cole's cancer saved his life, but there are side effects to his motor skills that may last his whole life. Growth hormones may help him grow, but nothing is for sure. Their lives won't be the same, and there are many unknowns. But they're figuring things out and supporting each other along the way.

As a family, an active lifestyle had always been important to them. Weekends are spent outside biking or walking with their 3 children. At the moment, Cole has trouble walking and he can't ride a 2-wheeled bike. The fact that he can't run and jump and skip like other kids makes him really angry and frustrated. Neither can he do other things that are important to a 10-year-old, such as print or cut things with scissors. All these problems make home life – and school – really hard.

Alana explains, "He'll come home and say, 'I failed because I can't do it and I'll never be able to do it,' and he'll throw his little fit. I get that he's frustrated about it. So we try to adjust in other ways." Alana worked with the school to find ways to help her son. Cole now has a laptop so writing isn't so frustrating. He has the help of a teaching assistant and went for testing to find out what his strengths and weaknesses are. Alana also got counselling from a social worker to find ways to help Cole deal with his anger.

Cole's older brother also tries to help – sometimes maybe a bit too much! If Cole's having a hard time riding his bike, Joe gives him a little push. And when Cole was being bullied, Joe stepped in. He wrote to the child who was hassling his brother, telling him that if he was at the same school he would "knock his socks off." Recalling this makes Alana laugh a little. "And the principal called us ... we had to try to talk to him about, you know, saying mean stuff to people. We know he wants to protect his little brother and it was nice to write the note, but next time he needs to say something different. He can't be mean about it."

At the moment, they can't predict what Cole will be able to do as an adult or how independent he'll be. Some survivors of medulloblastoma don't get back the motor skills that allow them to learn to drive a car when they're older. Alana and her husband invested in a house down the road when it came up for sale, just in case Cole needs it as an adult. They want to be nearby.

In the meantime, an active family lifestyle is still possible – on their terms. They got training wheels for Cole's bicycle and a stroller to take on walks in case he gets tired. "It's not a big deal. And we've kind of downsized exactly how much stuff we do, which is OK. You adjust." They reassure Cole that it's OK, that he doesn't have to be able to do everything he used to. After all, there are other kids who can't, too.

## Feelings

Happiness and relief at the end of treatment are often mixed with worry about the future and other feelings. You or someone in your family may be sad or angry about how hard the treatment was for everyone. Brothers and sisters may feel jealous or resentful or that parents are still too focused on the child who had cancer. It's normal to feel like you just can't take any more. After treatment, the whole family has more time to think about the experience. During treatment, everyone is so focused on just getting through each day. The strength of the feelings may surprise you.

“ 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 while 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.

Many parents feel lonely and isolated at first, now that that they're not seeing the healthcare team so often. They miss the regular contact with nurses, doctors and other people who were a big part of their lives, and the comfort that the contact gave.

“ You get used to seeing those nurses there. They give you that security blanket, I guess, and all of a sudden you're at home and as annoying as the nurses were at nighttime coming in to the hospital room and bugging us, you start to miss it. And you miss it because they're there to reassure you that everything is going well.

“ It's just so much to process. You feel like you're lost. You've had that support and all of a sudden it's not there. Because even though you don't want to be in the hospital, you do. Because you know if something happens, they'll be there.

You may find that friends and family who supported you during treatment are not around as much. They think the worst is over. This was the case for Terry and his family when his daughter Isabella finished treatment at the hospital. Terry and his partner really appreciated their great friends who kept them well supplied with meals and support while in hospital. “But on the return home, all that just kind of stopped.” Terry found this hard. “We’re still in it. We’re not out of it. We’re not at the hospital, we’re at home, but we’re still in it.”

It can be hard to find people who understand the pressures and fears that you feel when treatment ends. It may seem that friends and family no longer understand your experiences or needs. Talking to other families who have been through childhood cancer can be helpful. But it’s also important to connect and build relationships with parents of children who haven’t had cancer. It’s all part of returning to a normal life in the community.

### *Symptoms of PTSD*

Over time, most people find ways to deal with mixed feelings and stress after treatment ends. But it is possible for a survivor or their family member to develop symptoms that are usually seen in people with post-traumatic stress disorder (PTSD).

These symptoms include:

- not being able to stop thinking about unpleasant memories of cancer
- extreme physical or emotional reactions (rapid heart rate, shortness of breath, nausea) when thinking about cancer
- trying to avoid reminders of cancer

Most people with these reactions don’t have all of them, but even having one can stop you from getting on with life.



I was sleep deprived and anxious. I was overwhelmed ... I went into a phase where I thought there was no hope. This word PTSD has been thrown around but I do believe it's applicable to children going through trauma and the parents. I do, I see it. You have to cope whether you can or not with your child. Because you're all they have. So that was the situation.

Some other signs to watch for include:

- changes in appetite and weight
- crying easily or being unable to cry
- constant tiredness and low energy level
- sleeping a lot or not sleeping well
- feeling hopeless or having thoughts of death, escape or suicide
- being more irritable than usual
- having less interest in activities that used to be enjoyable
- avoiding healthcare visits
- refusing to talk about cancer

Talk to your doctor if you or someone in your family has symptoms of PTSD. Your doctor may refer you to a mental health professional like a social worker, psychologist, psychiatrist or nurse practitioner. Treatment often includes some form of counselling, medicine or both.

### ***Worrying that cancer will come back***

While your child is having treatment, it feels like everything is being done to fight the disease. When treatment stops, you may feel more worried about cancer coming back. It isn't easy, but try to remember:

- Most childhood cancers never return.
- The chance of cancer coming back gets smaller the longer your child is off treatment.

- Your child's treatment was carefully planned. There's no evidence that making the treatment longer means it would work better.
- For many children, there is still hope of a cure even if the disease comes back.

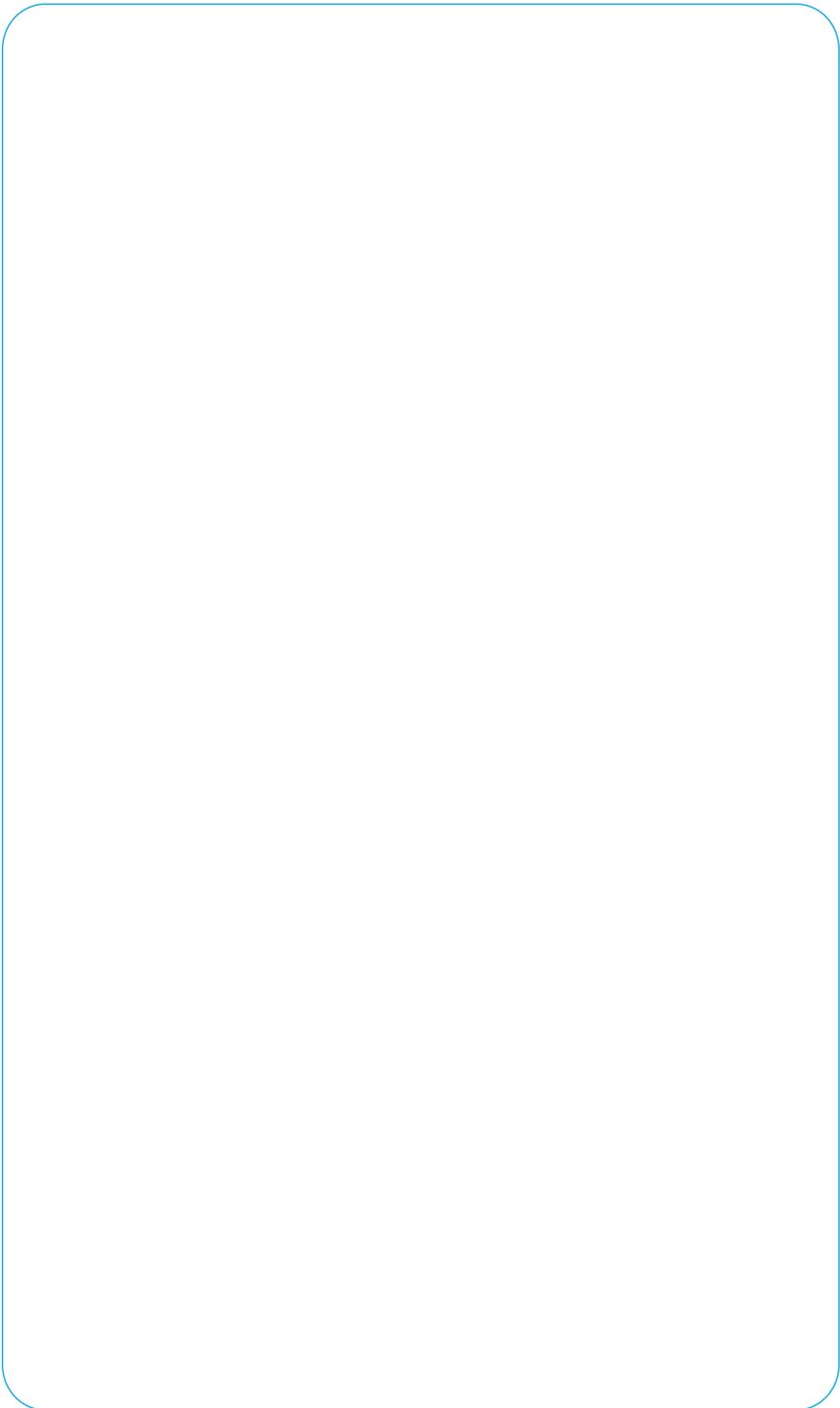


We'd have the results by the time we left saying that the bone marrow was good. But there was a second chromosome test that they would do that would take anywhere from 1 to 2 weeks to get the result. That was a bit stressful because that was really the one that would tell us whether everything was fine.

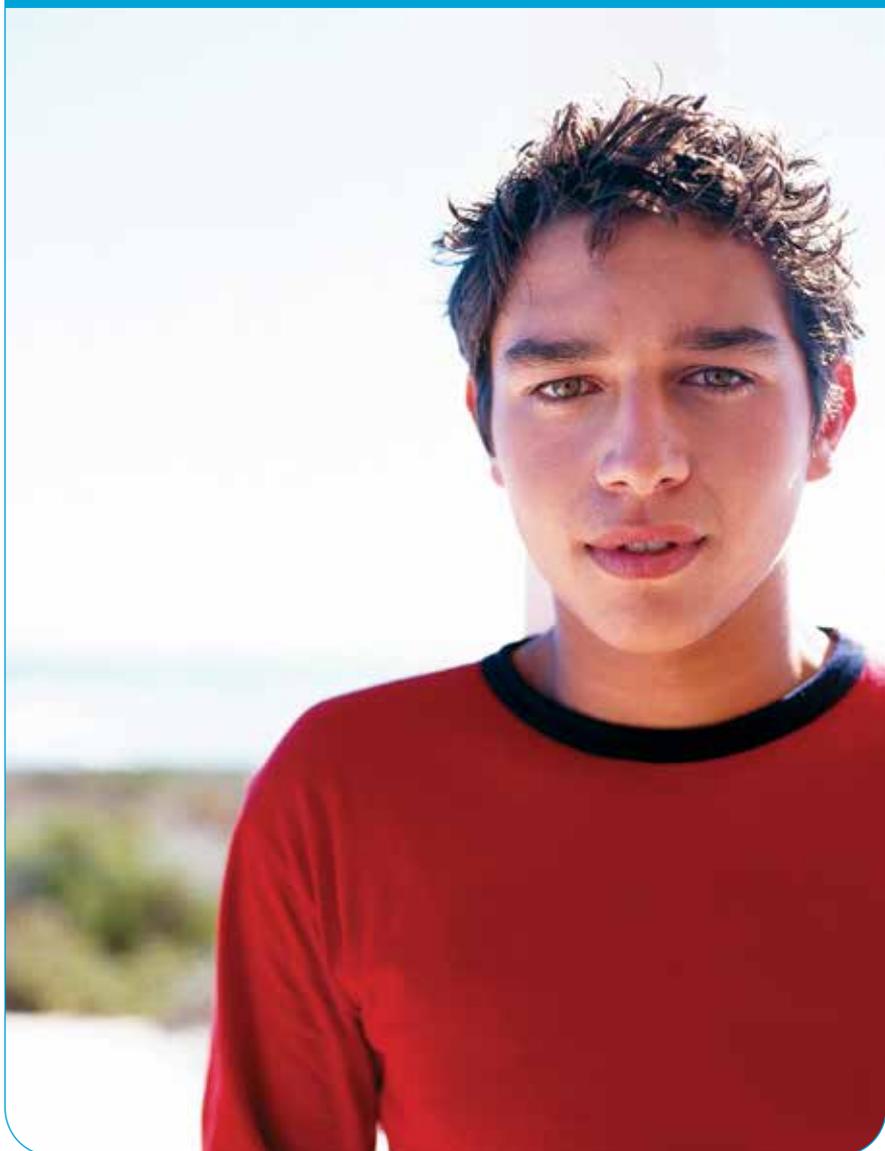
### **When to call the healthcare team**

All children get sick sometimes. There are some symptoms that might be signs of more serious illness or signs that the cancer has come back. Contact your healthcare team if your child has:

- a fever (your healthcare team will tell you more about what to watch for)
- bruising that you can't explain
- weight loss that you can't explain
- repeated headaches or vomiting early in the morning
- large or swollen lymph glands
- changes in mental state like confusion or unusual sleepiness
- changes in bowel or urinary habits
- unexplained lumps or bumps anywhere on the body
- any other concerns that worry you



## Moving forward



There's no protocol to follow as your family moves forward with life after cancer. As Joanne says, "It's really tough, but you have to keep on chugging. Eventually you'll see the light at the end of the tunnel." For many years, you may move between the positive and the negative, between relief and fear or joy and grief. Be kind to yourself and to each other as life goes on. It takes time – maybe more time than you imagine – to come to terms with all that has happened.

“ Often we get friends who say, we don't know how you did it. My only response is if you were put in that situation you would do it as well. You don't have the choice to deal with it or not deal with it, you have to deal with it.

Talk together about what you may have learned or gained from the experience of cancer. It's part of your child's life story. Your child may want to learn more about their cancer as they get older. Many will have been too young to remember or interpret their experience. Parts of it may have been too hard to talk about at the time. It's tempting to try to protect your child from this. But talking to your child about their cancer can be healing. It allows them to share their thoughts and feelings. As your child grows and continues with long-term follow-up care, include them in the conversations. This will help correct any misunderstandings and help your child feel more secure. It can also encourage them to ask questions. Over time, this will help them take responsibility for their own health.

You may want to share your hard-won knowledge with others.

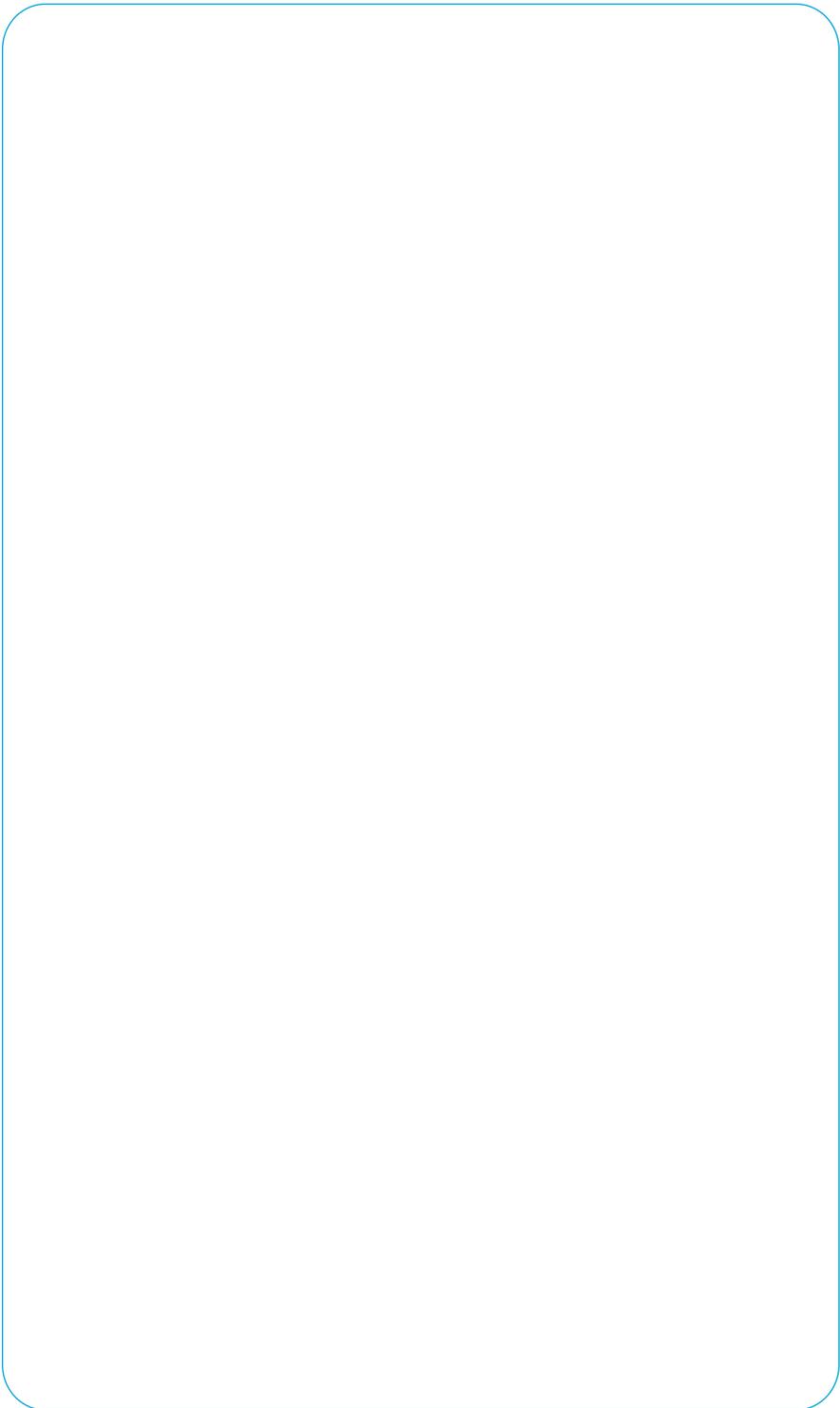
“ Whenever a fundraising event comes up, we always have our son there because we can give our time. He likes doing those sorts of things. He'll do the Ronald McDonald House McHappy Day. He sits there and hangs out and lets people ask him questions. We do the Game-a-thon because he likes playing video games. And if I can go somewhere and bring awareness or answer a question or do something, I'm happy to do that. We try. We try to help where we can.

Some families say they learned a lot about cancer, about caring for someone who is sick and about learning to speak up for what they need. Other families say they appreciate little things in life and feel much closer to each other.

“ I don't think of the cancer very often anymore. I probably should think of it a little more. When she's being a troublemaker – to put it politely – I have to remember what she's been through. But now everything is fine. She's a normal kid. We have some minor issues, behavioural stuff, but we're working through them.

“ 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.

“ 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



## Canadian Cancer Society

*We're here for you.*

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

**Call our toll-free number 1 888 939-3333.**



**Ask** a trained cancer information specialist your questions about cancer.

Call us or email [info@cis.cancer.ca](mailto:info@cis.cancer.ca).



**Connect** with people online to join discussions, get support and help others.

Visit [CancerConnection.ca](http://CancerConnection.ca).



**Browse** Canada's most trusted online source of information on all types of cancer.

Visit [cancer.ca](http://cancer.ca).

Our services are free and confidential. Many are available in other languages through interpreters.

### **Tell us what you think**

Email [cancerinfo@cancer.ca](mailto:cancerinfo@cancer.ca) and tell us how we can make this publication better.





## What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

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



Canadian  
Cancer  
Society

1 888 939-3333 | [cancer.ca](http://cancer.ca)  
TTY 1 866 786-3934

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