



## When your **CHILD** has **CANCER**

**CHILDHOOD BLOOD CANCERS DO NOT HAPPEN AS A RESULT OF SOMETHING YOU OR YOUR CHILD HAS DONE.** There is nothing you could have done differently to prevent a diagnosis. Our understanding of blood cancers in children has come a long way over the past few decades. Many children survive a blood cancer diagnosis today. As a parent, you can take an active part in your child's follow-up care, being aware of long-term and late effects of treatment, helping your child return to school and even dealing with your emotions. They are all things you'll need to manage to give your child the best possible quality of life through treatment and in the years that follow.





## Talking to your child about their diagnosis

Children are usually aware when their health is a cause for concern. Your child may experience a variety of emotions, such as anger, guilt, fear, anxiety and sadness, all in quick succession. Some parents wish to keep information about the illness and its treatment from their child to protect them from experiencing those feelings. Keep in mind that your child will use their imagination to fill in gaps of information. Being open about the illness and treatment helps your child build trust in both you and members of the healthcare team. It will help them feel more comfortable with the idea of talking about any fears and concerns when they come up. Encourage your child to talk about their concerns and ask questions. It may help to introduce your child to the healthcare team members who provide psychosocial support, such as a psychologist, nurse, social worker or child-life specialist.

### Age-appropriate discussion

It's better to talk to your child about their diagnosis in a way that is appropriate for their age. Consider the following guidelines.

#### **Baby/Toddler (0 to 3 years)**

- Infants and toddlers do not have an understanding of illness or cancer. Instead, they are aware of changes to routines and the feelings of people around them.
- They may be afraid of new faces and new routines like the medical staff and medical procedures.
- They may be afraid of abandonment or being left at the hospital. Offer physical and verbal reassurance.

#### **Preschool/ Kindergarten (4 to 6 years)**

- Children of this age may have some understanding of an illness like a cold, but may not grasp the implications of a serious illness.
- You may see signs of regression in a child's behavior, such as thumb sucking, bed wetting or tantrums.
- Their primary focus will be the symptoms they are experiencing in any specific moment. They may be afraid of pain, so explain tests or treatments to them in advance. Assure your child that they did nothing wrong to cause the cancer.



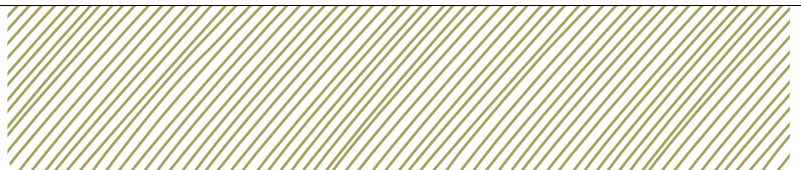


**Elementary/  
Middle School  
(7 to 12 years)**

- Children in this age-group may have a better understanding of serious illness, but not specifically cancer. They may have heard things about cancer at school, from friends, on TV or they may have found information on the Internet. Ask your child what they know and correct any misunderstandings, especially those that cause distress.
- Talk to your child, in advance, about possible changes to their physical appearance.
- A child may use play to process the information, play-acting doctor/patient scenarios for example.
- Explain tests, treatments, and other medical procedures in advance. Your child may be afraid of pain and resist some tests or procedures. Be honest. If a procedure might be painful, work with the healthcare team and decide how to explain what will be done to lessen pain and why the procedure is important.
- If the cancer treatment will result in any changes to the child's daily routine, explain to them ahead of time so that your child knows what to expect.

**High School/  
Teenagers  
(13 to 18 years)**

- Teenagers understand more about cancer and may want to know more. You may still need to correct any misinformation your teen has heard about cancer from school, friends, TV, movies or has found online.
- Teenagers may want to participate in decisions about their treatment. Include them in discussions with members of the healthcare team, as appropriate.
- You may need to discuss fertility preservation with teenagers. Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, needs to be done before treatment. Enlist members of the healthcare team to help with this sensitive discussion.
- Your teen may also be very concerned about changes to their physical appearance, such as hair loss and losing or gaining weight, as well as, worrying about how their peers will react to the changes.
- Be patient and give your teen a chance to talk too. Listening is as important as talking to your teen. As teenagers struggle to find independence, a cancer diagnosis may feel like a setback that can lead to feelings of frustration and anger. They may try to test their boundaries or engage in risky behaviors like drinking, drug use, or sex.





## Ways to help your child cope

It will help your child cope with their diagnosis if you:

- Provide structure to increase your child's sense of control. Children crave structure in their environment. Make things as consistent as possible. For example, plan a regular routine that you will follow during your time together in the hospital or clinic.
- Use positive reinforcement, such as giving encouragement, can promote the behaviours you want to continue seeing from your child. Acknowledge your child when they are doing difficult things.
- Use the same consequences for bad or inappropriate behavior as you did before your child was diagnosed with cancer. Consistency and routine will maintain structure and normalcy.
- Show that you respect your child's anger, worry, sadness or fear. Give your child appropriate outlets for expressing these feelings, such as drawing or keeping a journal.
- Keep your child busy with activities during treatment to take their mind off difficult and unpleasant experiences.
- Help your child to stay connected with friends from home and school with phone calls, emails, or visits, if possible.
- Ask for professional assistance for your child if they are having an especially difficult time adjusting to the cancer diagnosis and its treatment.

## Siblings

Everyone in the family is affected by your child's cancer experience, including any brothers and sisters. Siblings can feel angry, anxious, lonely, sad, guilty, or even resentful of the new attention their sibling receives. You can help your children cope with a sibling's diagnosis in some of the following ways:

- Give them the chance to talk about how the experience is affecting them.
- Be open and willing to answer questions about their brother or sister's cancer and treatment.
- Reassure younger siblings that they cannot "catch" cancer from their brother or sister.
- Explain that their brother or sister didn't do anything that caused the cancer.
- Warn siblings that their brother or sister may have less energy or lose their hair.
- Explain that other concerned family members and friends may ask them about their sibling's diagnosis.

### Talk about appropriate responses

Remember that brothers and sisters still have their own problems, unrelated to their sibling's cancer. Their problems are real and require your attention.

- Provide consistent, fair discipline to all your children, even though it may be more difficult right now.
- Let all your children know that you love them and are proud of them.
- Ask friends, family, other parents, and teachers for help. Disruptions to routines are inevitable, and siblings may feel lost or overlooked. Arrange for regular "alone time" with each child.
- Siblings need to continue to go to school and participate in their usual activities, as much as possible.
- Make sure the school is aware of the diagnosis. Talk to the sibling's teacher. Ask your hospital's social worker or psychologist or your school psychologist whether your community offers any programs for siblings of children who have cancer.



## School

School is a place for learning and fun so children benefit from returning to their classrooms as soon as medically possible. Most children who have cancer will attend school at least some of the time, both during and after their treatment. Let your child's teachers, nurses and guidance counsellors know what's happening.

Returning to school after cancer treatment can be a tough adjustment for young survivors. Your child may worry about returning to school, including fears about

- The reaction of friends and other children at school
- Missed schoolwork and social activities
- Changes in their abilities
- Changes in their appearance

Discuss any fears your child may have about going back to school. Help your child develop coping strategies for situations they might face. You'll need to ensure that your child's education is started, maintained or changed as needed. Take the following steps to ensure that your child gets the support that's needed at school:

- Meet with school administrators, teachers and counsellors as soon as possible after diagnosis to discuss your child's medical condition, and address any special needs or concerns with them. Work with the physical education teacher to ensure there is a safe way for your child to participate in activities. Discuss any evaluations that may need to be done to provide your child with extra support, such as physical therapy, occupational therapy, or other educational interventions needed.
- Ask school staff members to tell you about any issues that arise and provide you with relevant information.
- Let your child meet with their teacher(s) before returning to school to reduce anxiety.
- Ask your child's doctor to write a letter outlining your child's physical limitations or medical needs, such as the need for extra snacks, water or bathroom breaks. Meet with school administration and teachers to discuss these needs and how they will be accommodated. Ask the treatment team for expertise in explaining this information.
- Ask to give an age-appropriate class presentation, either before or once your child returns to school, to educate friends and classmates about the illness. Ask the treatment team for assistance. Some treatment centres have healthcare professionals available to lead these presentations.

## Long-term and late effects of childhood cancer

Treatment for childhood blood cancer involves risks for long-term and late effects that may affect

- Learning (cognitive effects)
- Psychological development
- Physical development
- Risk of a secondary cancer
- Fertility (ability to have biological children)

Specific effects depend upon your child's age, gender, type of treatment and additional factors. The range and severity of potential long-term and late effects vary. Some children will have no significant effects or very mild effects, while others may have more serious complications. However, early intervention and healthy lifestyle practices (not smoking, good nutrition, exercise, regular screenings and follow-up care) can help lessen the occurrence and/or severity of any late effects.

Ask your child's treatment team the following questions:

- What signs or symptoms indicate a long-term or late effect?
- Whom should I contact if my child develops any of these symptoms?
- What can we do to reduce the likelihood or severity of long-term or late effects?
- Can you provide printed lists of possible effects and signs or symptoms? What are the possible long-term and late effects my child may experience?
- Can you provide a list of routine screening tests and when they should start (for example, a mammogram)?

### Follow-up care

Follow-up care after treatment ends is a very important factor in your child's health and well-being. Even if your child is feeling well, keep all follow-up appointments with the healthcare team. Keep copies of all medical records, including dates and locations of treatment, specific drug and supportive therapies (such as blood transfusions), as well as dosages, specific sites and amounts of radiation therapy, if applicable. Keep copies of blood, marrow and imaging test (MRI, CT scan, x-ray) results. You and your child (when he or she is an adult) will need to share this information with future healthcare professionals. Help your child develop and maintain a healthy lifestyle after treatment ends, including appropriate exercise, sun protection, good nutrition and not smoking. Enlist the help of healthcare professionals, as needed.



Use worksheet:  
*Appointment Details*



Use worksheet:  
*Appointment Calendar*



Use worksheet:  
*Healthcare Team Contact List*



Use worksheet:  
*Medicine Log*



## Managing your emotions

You are likely to experience a wide range of emotions from the time your child is diagnosed with cancer, throughout treatment, and beyond. These emotions may include shock, denial, fear, anger, guilt and sadness. You may feel that life for your child and family will never be the same. Allow yourself to feel sad. Understand that you are not to blame for your child's diagnosis. Over time, you'll find ways to adapt and gradually develop a new sense of normalcy for you and your family. All of these feelings are to be expected, but if you feel consumed by feelings or are unable to function, seek professional help. Psychologists, social workers and spiritual advisers may also help you come to terms with your child's diagnosis. It's important to work through your feelings so you can help your child to cope and you can continue to manage other aspects of family life and work.



Don't be afraid to seek help. The Leukemia & Lymphoma Society of Canada offers a number of helpful resources. For more information about how we can help you, visit [bloodcancers.ca](http://bloodcancers.ca) or ask to speak with a member of our Community Services team at 1-833-222-4884.



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