



Talking With Your Child About Their Cancer Diagnosis

THE
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FOR WOMEN'S
CANCERS



Canadian
Cancer
Society

SickKids®

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Cancer Centre

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Introduction

Many childhood cancer survivors benefit from lifelong healthcare related to their cancer treatment. Their cancer treatment may lead to long-term side effects. However, many survivors of childhood cancer do not complete regular recommended screening. One reason why childhood cancer survivors report that they do not receive the recommended care, is that they do not know that they had cancer. They also might not know enough about their cancer diagnosis and treatment to be able to advocate for themselves.

Children who know about their cancer history have an easier time understanding their appointments and are more involved in their care. Knowing about their cancer history also helps them build trusting relationships with their parents and healthcare providers.

Many parents feel overwhelmed thinking about talking to their child about their cancer diagnosis. When parents think about how challenging it could be to have that conversation, they might be unsure of exactly how and when to start. But once they start talking, parents often feel relieved and are reassured by their child's response.

This booklet is a guide for you and your family. The information in this booklet will help you start planning how to talk with your child about their cancer diagnosis. You will find ideas, tips, and resources to make it easier to talk with your child. You can also speak with members of your child's healthcare team for support or for more information. It might seem hard to start but remember that you are not alone.

CULTURAL CONSIDERATIONS

Culture may have a huge influence on how cancer is experienced and discussed. Culture can affect who, when and how the conversation starts. There is no right or wrong way to discuss a cancer diagnosis, as every individual and family is different.





"I was relieved to be honest, that she knew what she went through. Not exactly the details, but she knew what she had, and she was able to ask questions."

— Mother of acute lymphoblastic leukemia survivor

Talking with your child: Why is it so important?

BENEFITS OF TALKING

- Helps family members feel more comfortable talking to one another, which can bring a family closer and feel more connected.
- Builds mutual trust between a child and their parent(s).
- Establishes a collaborative relationship between your child and their healthcare providers.
- Prevents misinformation such as “cancer is contagious” and clarifies myths.
- Gives the child the chance to react and ask questions (e.g. why they have scars or why they go to a cancer clinic).
- Allows the child to process emotions, feel more secure, and less anxious.
- May create a sense of strength, independence, and confidence in the child.
- Empowers the child to take care of themselves.
- Gives the child knowledge about their health, which allows them to recognize if something is wrong and seek appropriate care.
- May result in parent(s) feeling a sense of relief.

RISKS OF NOT TALKING

- A child may learn about their cancer diagnosis from someone or somewhere else and may miss the chance to first ask their parent(s) about what happened.
- Children often sense when information is kept from them, and they might make up their own reason about why they are not being told certain information.
- The trust between a parent and a child may be affected if they learn that information has been withheld.
- A child may wonder what else am I not being told? Often, their unstated worries may be worse than the reality.
- A child may not feel comfortable showing their emotions or understand that it's OK to feel a certain way.

HELPFUL TIPS FOR TALKING

Talking with your child about their cancer diagnosis can be challenging. As a parent, your first reaction may be to protect your child by keeping information from them or by delaying the conversation. These feelings are normal.

Here are some tips that have helped other parents feel comfortable talking with their children about their cancer diagnosis. Feel free to use the tips that feel right for you:

Ideas and Suggestions

- Ask your child's healthcare team for resources like a booklet or trusted website. You can also ask your child's healthcare team about any information that you don't understand.
- Meet with your child's healthcare team to talk about questions your child may ask.
- Ask other family members, friends, or your child's healthcare team to help you practice having the talk. Practicing will help you feel more comfortable.
- Find information on words that children understand, depending on their age.
- Talk with your child in "small steps."

Emotional Support

- Talk to your child's healthcare team, who can support and encourage you.
- Meet with a psychosocial provider (for example, psychologist or social worker) to help with your own emotions.
- Consider connecting with other parents who may be able to provide support. But remember, what works for other parents may not work for you.
- Meet with other professionals (for example, a child life specialist) to understand how your child may show their emotions and how to support them.

Positive Effects of Talking With Your Child

- Friends and family can help support you and your child.
- Realizing that your child may not need to be treated in a "different" way.
- Empowering your child to better understand their body.
- Learning that your child is more resilient than you had thought.
- Your child may not react as strongly as you had imagined.
- Your child may not see their diagnosis in a negative way.



"Once I told my son, he started calling himself a 'superhero.'" — Mother of neuroblastoma survivor

Choosing a time and place to talk

You may want to delay talking with your child about their cancer diagnosis, and this is understandable, but most children can sense when something is off. They might make up their own reasons for why their parent(s) seem worried or why they keep visiting a hospital for appointments and tests. Often, the explanations they create in their heads are more distressing than the truth.

The sooner your child knows about their cancer history, the sooner they can begin to understand it and benefit from the whole team's support.

Here are some tips on finding the right time and place to talk with your child:

- Choose a time when you can sit together without interruptions or distractions.
- Make sure there is time for your child to ask questions, but do not worry if they have none. Children will ask questions in their own time.
- Choose a time and place where everyone is calm, like a casual meal, a walk, or a weekend drive.
- You can start the talk during your child's next clinic visit. Their healthcare team can be there to help.

TIME TO TALK

- It is okay to not have all the answers. You and your child will continue to talk about this over time.
- Talking to your child before bed or before an important event may not give your child time to process the news or ask questions.
- Talk to your child when you are not feeling overwhelmed.



"Most of these challenging discussions typically happen on our walks. We walk a lot as a family, we go for hikes. Those are, I found, really good times to have the discussion. You can walk next to each other, there is no phone or distraction."

— Mother of papillary thyroid carcinoma survivor



Who could talk with your child?

Talking with your child about their cancer diagnosis can be challenging but rewarding. The information about their cancer diagnosis should come from someone your child trusts. If you are part of a 2-parent family, find a time when you and your partner can be there to support your child and each other. If you are part of a 1-parent family, you could include another adult that your child trusts or another family member. Your child's healthcare team is always there to support you and your child. If you have a particular faith or religion, hospital spiritual or religious leaders can also give you and your child comfort, support and direction.

How to support your child as they learn about their history

Children may react to the news of their diagnosis in different ways. How children react may depend on their age. They may already have guessed, or they may be surprised. They may accept the news, or they may be confused and scared. They may ask for more details, or they may be bored with the medical talk. Whatever they are feeling is okay.

As your child learns more, they will gradually understand that they had cancer in the past, and the chances are that their treatment is behind them, and they can move forward in life.

There is no specific age to tell your child about their cancer diagnosis. But children as young as 3 years old can be told about their diagnosis using words that they understand.

SIBLINGS

- Siblings may also need support. They may have questions and want to know more about their sibling's cancer diagnosis.
- Consider when it would be a good time to talk with siblings.
- Siblings can also talk with each other and support one another.



How to talk with your child

There are different ways to talk with your child about their diagnosis. How you share this with them will depend on their age and developmental stage. Your child may also need help understanding medical terms for their illness or treatment.

- A. Prepare in advance:** Consider practicing the conversation and roleplaying what you would like to say before speaking with your child. You may want to practice with your partner, friend, or healthcare provider. It may also help to think about some questions your child might ask you.

Common questions a child may ask when told they had cancer:

- What is cancer?
- Can you catch cancer?
- Why did this happen?
- Did I get cancer because of something I did?
- Will I have to keep going to the hospital forever?
- Do I have to get scans/tests/needles every year?
- Will the cancer come back?
- Will I die like grandpa or another relative?

- B. Be open:** Don't be afraid to use the word "cancer". Words such as "the big C" or "bad cells" can be confusing for children. You may want to start by asking your child what they already know about cancer. Many children think cancer leads to death because of what they learned from a previous experience – with a family member, pet, or through the media (for example, Terry Fox). It is important to correct myths and ideas that are wrong and help them understand that not all cancers are the same. You may want to remind them of someone you know who had cancer in the past and is doing well.
- C. It's OK not to know:** Understand and accept that you will not have all the answers. Be prepared to say, "I don't know. Shall we put that on our list to ask at your next appointment?"

- D. Reassure:** Make sure your child understands that the cancer was not their fault and that they didn't do anything to cause the cancer. Also, be clear that people can't "catch" cancer and that it does not spread from one person to another.
- E. Don't overload:** Give your child time to think about what you have told them. Also give them time to ask questions. Some children may not have a lot of questions at first. Accept that they will talk when they are ready. Try to answer questions as honestly as you can. How much information you give your child will depend on your child's age and how much they understand. Just remember, conversations are usually ongoing.
- F. Comfort:** Ask your child how they feel about what you have told them. Check on them often to see how they feel. Take the time to listen to their fears because it can help them cope and may also reduce their worries.

STRONGER TOGETHER

Let your child know that they are not alone and that you will always be there for them. This simple message can be very reassuring.



Conversation starters

Here are some examples of how to start the conversation:

- What do you remember about this clinic?
- Why do you think you're here?
- You know how we visit the hospital? The reason we go there is...
- Today, I want to share more information with you about why we go to the hospital. Why do you think we go there?

Here are examples of how your child may respond depending on their age group:

PRESCHOOL-AGED (3-5)

- May not understand what cancer is but have a basic understanding about being sick or feeling sick.
- May believe that their thoughts and actions affect the world around them (“magical thinking”). When they are told about their cancer diagnosis, they may think, “Did I cause it? Did I do something bad?” They will feel reassured when you explain that cancer could not be caused by anything they did.

SCHOOL-AGED (6-12)

- May understand more detailed information about cancer. They may know what cancer is from hearing about it at school or from knowing a relative with cancer. Let them know that there are many types of cancer and how someone is affected can be very different from one person to the next. Be open and honest, and let them know that they have a whole team taking care of them.
- May feel different from their peers but will gradually understand how they are different and how they are the same, as we all do.
- May blame themselves for the illness and will feel reassured when you explain that cancer could not be caused by anything they did.

TEENAGERS (13-18)

- May understand complex information about cancer and may have many questions.
- May not understand information that they find online. Encourage your child to talk to you about where they get their information. Your child can also ask their healthcare team about where to find reliable online information.
- May know what cancer is and what diagnosis, treatment and prognosis mean. But they may not have all the correct information.
- May feel different from their peers but will gradually understand how they are different and how they are the same, as we all do.
- May accept that they had cancer, and they may want to be proactive about taking care of their health.
- May need privacy. They may want to talk only to certain people about their history of cancer. Respect their privacy and let your teen decide who and when they want to tell.

Resources

- About Kids Health (SickKids):
<https://www.aboutkidshealth.ca/>
- Canadian Cancer Society:
<https://cancer.ca/en/living-with-cancer/your-child-has-cancer>
- Pediatric Oncology Group of Ontario:
[https://www.pogo.ca/wp-content/uploads/2021/12/Can I Catch Cancer Web 2021.pdf](https://www.pogo.ca/wp-content/uploads/2021/12/Can_I_Catch_Cancer_Web_2021.pdf)
- St Jude's Children's Hospital:
<https://together.stjude.org/en-us/for-families/talking-to-your-child-about-cancer.html>
- Young Adult Cancer Canada:
<https://youngadultcancer.ca/>
- Gilda's Club Toronto:
<https://www.gildasclubtoronto.org/>
- Kids Help Phone:
<https://kidshelpphone.ca/>
- Canadian Mental Health Association:
<https://cmha.ca/>
- Bounce Back Ontario:
<https://bouncebackontario.ca/>
- Family Navigation Project (Sunnybrook):
<https://sunnybrook.ca/content/?page=family-navigation-project>

Other helpful tips

1. Keep it simple: help your child understand the basic facts about cancer.
2. Use age-appropriate words and explain terms they don't understand.
3. Don't be afraid to use the word cancer.
4. Be clear that no one caused the cancer.
5. Encourage your child to ask questions and to share their feelings.
6. Know that it's OK to say, "I don't know" and "let's ask."
7. Accept that your child will talk when they are ready.
8. Think about how much information to share at one time.
9. Allow your child to lead the conversation with their questions.
10. Watch your child for cues: if they look distracted, they may have had enough information at that time.
11. Confirm truths and correct misinformation.
12. Be a good listener: take time to listen to their worries or concern.
13. Balance hope with reality, but do not make promises that you cannot keep.
14. Use resources that are available to you.
15. Let them know that they are not alone.

Your child's healthcare team is always available to answer questions or help you talk with your child.

Notes

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