

# Cancer Conversations WITH YOUR Kids

How to talk to your children about cancer.



# Table of Contents

- 2 Introduction
- 4 Preparing to Talk to your Children

### 5 Talking to your Children

Child-friendly explanations The Four C's Infants and toddlers up to 2 years of age Children 3-5 years of age Children 6-8 years of age Children 9-12 years of age Children 13-18 years of age

- 20 Ways to Check Back in
- 22 Facing End of Life
- 24 Common Questions and Statements
- 26 About Nankind
- 27 Resources and Books

# Introduction

Nankind has developed Cancer Conversations with your Kids so parents with cancer can speak with their children about their diagnosis in a language children can understand. This is designed as a guide to help you have this delicate conversation with the goal of reducing your child's fear and anxieties.

As a parent, we always want to protect our children from any type of harm or sadness. This is especially true when discussing your cancer diagnosis. You may be worried about increasing your child's fears, saying the wrong thing, becoming emotional, or that your children just won't understand. You are not alone. Research shows that when children are not included in discussions about serious illnesses, they may react negatively to changes in their routines and relationships. They may fill in the gaps with information on their own. Many times, their magical thinking is much worse than reality. They wonder if they caused your illness if they can catch it, if they can cure the illness, and they worry about who will care for them if mom or dad dies.

## nankind

# Preparing To Talk To Your Children

When preparing to talk to your children about your cancer and your diagnosis, we would recommend the following:

Plan to have the conversation in a familiar place, where your child feels safe and comfortable. This is most often at home. Make sure the space is free from distractions so that both you and your child can focus on the conversation. You do not have to have this conversation alone. Include any other caregiver,

family member, or trusted friend who knows your child well.

Be open, honest, and tell the truth. This will make the conversation easier and relieve you of additional Get on the same level as your child. If they like to sit on the floor, sit on the floor with them.

stress. Practice saying the phrase, "I have cancer." This is difficult and can feel overwhelming, but it is important to name your illness in order to educate and empower your children to talk about cancer. Think about what you want to say and how you want to say it. Take some time to imagine how you think the conversation will go. The younger your child is (5 and younger), the shorter their attention span, so having a few phrases prepared and practicing them will help you communicate.

Depending on how much information your child wants to know, you may want to have paper and crayons or pictures to help explain what a cell is, the part of your body where there is cancer, or how a tumour forms. Playdough or plasticine also works and makes it easy to engage your child in the conversation.

# Talking To Your Children

- 1 There is no perfect time to talk to your child about cancer. You may want to wait until you have enough information from your doctor about your diagnosis and treatment before telling them, but this is not necessary.
- 2 Listen to your child. Depending on the age of your child, you may need to repeat some of the information, and this is okay. If you have children of different ages, one may want more or different information than the other and that is also okay. Take the time to address each child's needs separately.

If there are questions you do not have the answers to, that is okay. Respond to your child honestly, and let them know that you need to check with the doctor or another professional to answer their questions. You do not need to share the information all at once as it can be overwhelming or confusing. Keep the option open for your child to ask for more information later.

- 3 Educate your child about your cancer. Your child might have misconceptions about what cancer is or may have access to unreliable information. While they don't need a lot of detail about the illness, help them name your cancer and understand where it is in your body.
- **4** Each child may react differently, and that is okay.

5 At the end of the conversation, make sure to talk about next steps and that you will check back in. Encourage your children to initiate a conversation about their feelings or questions they have about your cancer, but remember they will most likely need an adult to take the lead.



### Child-Friendly Explanation Of Cancer

The body has millions of tiny cells that grow and have special jobs, like skin cells or blood cells. Cancer cells don't have any job and they grow too fast. When there are a lot of cancer cells, they create a big group of cells called a tumour. Cancer is something that happens by nature. We don't know why it happens, but we have special medicine and treatment that can help make the cells smaller or stop growing.

#### Child-Friendly Explanation Of Treatment

There are different types of medicine that the doctors will use to try to stop the cancer cells from growing. I will have to go to the hospital for this medicine. Sometimes it will make me very tired or throw up and I might lose my hair. You might see other things about my body change too. It may be very scary, but this is normal for how a body responds to the medicine.



It Is Never Too Late To Have The Cancer Conversation There is no perfect time to talk to your children about cancer, but it is never too late. Children will always benefit from being included in the cancer journey even if they are included halfway through treatment, during recovery, or at the time of palliative care.

If you choose not to share this information with your children, there is a risk that they will find out by overhearing an adult conversation. When this happens, not only does magical thinking kick in as a coping mechanism, but kids may build a wall of mistrust and secrecy. They may believe they have not been told about your cancer because it is a big secret, and they may think they need to protect you by keeping the secret. This can be a tremendous burden for any child of any age.

Remember to stay honest. Discuss your anxieties about sharing this information and be prepared to manage their anger or frustration in being excluded. It is important to acknowledge that you will continue to include them in your cancer journey moving forward and be mindful to do so in order to maintain trust.

# The Four C's

The four Cs are four common concerns that children have when someone they care about has cancer.



It is important to address these concerns even if your child hasn't brought them up to you. Often children do not share these questions because they don't want to upset you and they revert to magical thinking; making up their own answers and coming to their own conclusions.

### Can I Catch It?

Most children are familiar with colds, flus, and most recently, COVID-19. Children know they can catch these types of illnesses. Reassure your child that they can't catch cancer from you because it is not contagious. Carefully explain that they can safely touch, hug, and play with you even though you have cancer.

#### Did I Cause It?

Children often wonder about how their parents got cancer. Children are magical thinkers, meaning they believe their thoughts, ideas or wishes can affect what happens in the world around them. This is a natural part of their development; however, when children are not provided with the correct information it may cause them to believe they are responsible for your cancer. Kids may think "Mom kept yelling at me to clean my room and that's why she got throat cancer" or "I was so mad at my dad that I wished he would go away, and now he is in the hospital." Reassure your children that nothing they did or said is the reason you have cancer.

#### Can I Cure It?

Children often wonder if they can cure their parent's cancer. Children may believe if they meet all the behavior expectations (clean their room, complete their homework, get along with their siblings) then their parent's cancer will go away. It is important to ensure that your child understands that nothing they do or say can make your cancer go away. Remind them that you have doctors who are giving you special medicine to help fight your cancer and it is not their job to cure your cancer.

#### Who Will Take Care Of Me?

Children often wonder who will take care of them when their parent has cancer. They may wonder about who will pack their lunches, take them to soccer practice and play with them at the park. Remind them of all of the people in their lives that love them and reassure them that they will always be taken care of and loved.



# Infants And Toddlers Up To 2 Years Of Age

Although babies have not yet developed enough to engage in conversation, they will be attuned to changes in their routine and separation from you, their parent. A toddler's ability to understand concepts of illness greatly fluctuates and shouldn't be a barrier to sharing the truth about your cancer diagnosis. Even if they do not grasp the details of the illness, the earlier they are able to name it as cancer, the better equipped they will be throughout your treatment and recovery.

#### Signs To Watch For:

- Baby may become more cranky or clingy. Sleeping or eating habits may change.
- May more frequently throw tantrums, say "no," or show regression through behaviours like bed-wetting if previously toilet trained.

#### Ways To Support Your Child:

- Try to stick to their feeding and sleeping routines with other caregivers.
- Consistency with caregivers will benefit your child.
- Maintain familiar environments with blankets or toys that your child recognizes.
- If you are recovering from surgery or have limited mobility because of treatments, maintain proximity to your child so that he or she can still hear your voice in order to reassure them. If you can hold them with assistance, try to do this as much as possible. If not, physically being present in the room while your child is engaged in an activity, reassures them and calms their anxieties.



## Children 3-5 Years Of Age

At this age, children have a basic understanding of what it means to be sick but tend to construct their world in relation to themselves. It is important to give them the language to name your illness and reassure them that they did not cause your cancer, that there will be someone to take care of them and that they are an important part of your cancer journey.

It is also important to differentiate between the forms of sickness they are familiar with and a cancer diagnosis and to establish and reassure them that they need not worry about catching the illness so that you can maintain physical closeness.

#### Signs To Watch For:

- Children may become more fearful of monsters or the dark, strangers, or anything unknown. Incidence of nightmares may also increase as well as possibly talking in their sleep.
- You may notice increased separation anxiety when going to school or getting ready for bed, and your child may begin to repeatedly ask the same questions.
- Your child may begin to display increased aggressive behaviours like hitting or biting.

#### Ways to Support Your Child:

- Keep pictures, books, or other items on hand to help explain cancer in simple terms.
- You may find that you need to revisit the following concepts to comfort your child: they did not cause your cancer; that cancer is not contagious and they can still hug, kiss and be affectionate with you; remind them of who will continue to take care of them throughout your treatment.
- Keep as many routines the same as possible including discipline, regular exercise, and bedtime routines. This will reinforce stability, consistency, and help your child process their feelings.
- Find ways that your child can be helpful and support you throughout your treatment.

#### **Useful Phrases**

"I have something very important to tell you."

"There's something I need to talk to you about."

"I want to talk to you about the doctor appointments I've had."

"I want you to know that you can talk to me about any of your feelings."

"I know this can be confusing. Can you tell me what we talked about today."



# Children 6-8 Years Of Age

School age children are able to grasp a more complex definition of cancer and can participate in a conversation about your cancer diagnosis. Since they are only beginning to understand the concept of death, they may assume that all people who get cancer will die. They may believe unreliable information they learn about cancer, from their classmates or friends.

It is important to clarify the details of your diagnosis and give them space to digest the information and ask questions. At this age, some children may feel guilty about misbehaving and think that something they said or did may have caused your cancer.

#### Signs To Watch For:

- Your child may start to ask questions and be worried about the health of their other caregivers.
- You may notice that your child cries more often, or seems irritable or anxious more frequently.
- Your child's fear of new situations may increase and they may withdraw from family or friends. They may also have difficulty concentrating or paying attention at school. This can also manifest itself physically in the form of frequent headaches or stomach aches.

#### Ways to Support Your Child:

- Keep pictures, books, or other items on hand to help explain cancer in simple terms.
- You may find that you need to revisit the following to comfort your child: they did not cause your cancer; that cancer is not contagious and they can still hug, kiss and be affectionate with you; you should remind them of who will continue to take care of them throughout your treatment.
- Keep as many routines the same as possible including discipline, regular exercise, and bedtime routines. This will reinforce stability, consistency, and help your child process their feelings.
- Find ways that your child can be helpful and support you throughout your treatment.

#### **Useful Phrases**

"It can be scary to talk about cancer, and it scares me too, but it is okay to feel this way."

"You can tell me about any of your feelings—mad, sad, or afraid. If you have very strong feelings and they aren't going away, please tell me and we will work together."

"I don't have all the answers to your questions, but I will try to find them. We can ask the doctor or find someone who knows the answer."

"Cancer is not like a cold, you can't catch it or get sick. We can still hug and kiss each other."



# Children 9-12 Years Of Age

Depending on your child's previous experiences and maturity level at this age, they are beginning to understand themselves better and develop a sense of their personality and their place in the world. It is likely they have already learned some information about cancer at school or heard about someone's experience with cancer from a friend or classmate.

Their concerns may be more complex and include questions about how their role in the family may change, or they may start to worry about another healthy caregiver in their life (parent, grandparent, aunt, uncle).

They may hesitate to show any emotion in an attempt to protect you as a parent in order to show you they are "strong." It is helpful to model healthy ways of expressing and channelling feelings like anger, sadness, or fear, and remind them that it is also okay for them to feel joy and happiness.

### Signs To Watch For:

- Your child may seem withdrawn and lose interest in everyday activities, friends, or family.
- There may be times when your child reacts with an increased level of hostility towards you or other caregivers.
- It is possible that your child may start to worry about their own likelihood of becoming diagnosed with cancer.
- School marks may begin to suffer as your child struggles to pay attention in class.
- Your child may take on the role of a caregiver within the home, especially towards you and younger siblings.

#### Ways to Support Your Child:

- You may find that you need to revisit the following to comfort your child: they did not cause your cancer; that cancer is not contagious and they can still hug, kiss, and be affectionate with you; remind them of who will continue to take care of them throughout your treatment.
- Encourage your child to be open about their feelings and to express when they are feeling angry, sad, afraid, or anxious about your diagnosis or your treatment. Make sure to check in as often as possible to remind them that it is okay to talk about how they are feeling, as children are likely to avoid showing strong emotions to try to protect their parents.
- Remind your child that it is okay to also have fun and be happy throughout your treatment. This will also help maintain consistency and keep your child engaged in the activities that they normally enjoy.
- Find ways for them to be helpful around the house by giving them specific responsibilities so that they can see their impact as an important member of the family.

#### **Useful Phrases**

"I will start my treatment next week. Some things may change around our home, but there will be someone to take you to your soccer games."

"It's okay if you don't want to tell your friends. If you are feeling sad or do not want to talk, tell them nicely that you do not feel like talking. It is important that your teacher knows, so that you can talk to someoneat school if you need to."

"If you feel worried or have any questions, please come to me and we can talk about them"



## Children 13-18 Years Of Age

As teenagers are beginning to think and act as adults, they will be able to understand most, if not all, of the complexities of your cancer diagnosis and treatment. The experience of adolescence already presents many challenges as teenagers seek independence from their parents and begin to develop their own trusted relationships with friends and other companions.

#### Signs To Watch For:

- You may notice an increase in anger, depression, or rebellious behaviour. Often, teenagers will engage in riskier activities when anxious or insecure.
- Teenagers are more likely to hide their feelings from their parents and they may be critical or uncomfortable with the way the situation is being handled.
- Your child might be insecure about others finding out or asking questions about your cancer diagnosis, and may worry about being treated differently. They may also start to fixate on the possibility of becoming diagnosed with cancer.

### Ways to Support Your Child:

- Encourage your child to be open about their feelings and to express when they are feeling angry, sad, afraid, or anxious about your diagnosis or your treatment. It is important for teenagers that they have someone to talk to, even if they don't feel comfortable opening up to you. Encourage them to speak to a trusted friend or adult.
- Remind your child that it is okay to also have fun and be happy throughout your treatment. This will also help maintain consistency and keep your child engaged in the activities that they normally enjoy.
- Allow your teenager privacy when needed, but maintain established discipline in the home. It is important that there is still structure in the home to support your children. This also applies to continuing to talk to your teenager about everyday topics like their friends, school, homework or part-time jobs.
- Pay attention to how much extra responsibility your child is taking on throughout your treatment to make sure they don't take on more than they can handle.
- Make sure your teenager knows how and where to access other counselling and support resources outside of the home, such as Kids Help Phone.

### **Useful Phrases**

"I will be going for more tests and may need surgery before starting my treatment. I will let you know more information as I get it"

"I won't be able to move around as much, so I will need you to help out more around the house."

"I know you're faced with a lot of challenges as you are growing up and my cancer diagnosis is a new one. You will still be cared for and I want you to know that you will be included in this process as much as possible."

# Ways To Check Back In

#### Be Right Back Jar

This tool will help all family members talk about how they are feeling or ask difficult questions they may not be able to find the words to express.

#### ALL YOU NEED IS:

- 🔲 A jar or shoebox
- Strips of paper
- Something to write with: a pen, pencil, crayon, or marker
- Some string
- 🗌 Glue

Simply tie a piece of string to a pen and glue the other end of the string to the box or jar so that there is always something available to write with. You can leave blank strips of paper in the box or jar, or attach them to the outside.

As your children, your partner, or you have questions or concerns about your cancer diagnosis, treatment, or anything else, each person can write something down and place it in the jar. Choose a time to address the items in the Be Right Back Jar when you have few or no distractions and can do so in a comfortable and familiar place with your children.





#### Feelings Charts

Feelings charts or cards can be a helpful tool for your children at any age as they develop their emotional vocabulary. You can place a chart in a shared space in the home, such as on the refrigerator, where your child can place a magnet on top of the emotion that they are feeling that day. This can coincide with morning, after-school, or bedtime routines as well.

Alternatively, if your child is older or a teenager, longer formats of feelings charts are available. These have a larger variety of more complex feelings and can be printed and placed on the outside of their bedroom door. They can use a piece of sticky tack or a post-it note to indicate their feelings.

A Feelings chart allows your children to overcome barriers in expressing how they feel and can help you understand when they need to talk, even if they may be too nervous to initiate a conversation. This way, you can give your child another communication tool (https://www.avanmuijen.com/watercolor-emotion-wheel).

### Role Model Openness And Honesty

For children at any age, it is impactful for them to see their parents and other trusted adults in their life model open and honest behaviours. The more open you are about how you are feeling, the more comfortable your child will be talking to you about their own fears or anxieties. Children pick up most of their behaviours from how their parents, siblings, and other family members interact with each other. Setting the example can have a huge impact on how, when, and how often your child chooses to share their feelings with you, and will make checking back in much easier.

# Facing End Of Life

Preparing To Talk To Your Children About Death When you are facing end of life, we recommend the following:

### Check-in

- Let your child know that you need to update them on the progress of your cancer. Revisit the same tools that you used when you explained your diagnosis. Find a comfortable and familiar place at home to talk to your child and make sure there are no distractions.
- Double-check to see how much your child understands up to this point and repeat any information if necessary.

#### Prepare Your Child for a Death

- Remember, you do not have to have this conversation alone and you do not need to be the one who tells your children about the end of life. However, it will be very important that you are in the room with your child.
- Remember, it is okay to become emotional and/or cry with your child. It is also okay if your child does not have an immediate reaction, as he or she may need time to process the information.
- Explain what will happen physically to the body. Differentiate yourself from your body. For children of any age up to and including children 12 years old, a simple explanation of death is to explain that the body stops working and will not work again. Your child must understand that a body that has stopped working does not feel pain or cold, and does not breathe, smell, hear, or taste (Andrea Warnick, 2012).
- Ask your child how much information they would like about what might happen to a body as it dies: changes in breathing, skin colour, sleeping or eating habits. It will be important for another caregiver to check back in to make sure that your child can ask questions if they have any along the way.

#### When Death Occurs

- Ask your child how they would like to be involved. Do they want to be present at the time of death, informed at school or woken up at night. Whatever their decision, it is important to address any fears or anxieties they might have that could cause them to avoid being involved.
- Include your children in the funeral, celebration of life, or other end-oflife traditions or rituals that your family holds. It is important that they can contribute to this process so that they can continue to stay connected.



### Legacy Work

Some parents will write letters or prepare videos on special items to be given to their children at specific age milestones after their death. This is known as "legacy work". While this is important for some, others find it more meaningful to spend time being with each other and listening to their children share experiences. You must choose what is best for you and your children. The important thing to remember is to include them in the discussion.

### Child Friendly Explanation Of Dead

The body stops working and will never work again. The body does not feel pain or cold, and does not hear, see, smell or taste (Andrea Warnick, 2012).

### Child Friendly Explanation Of Grief

All of the feelings and thoughts when something hard happens in life (Andrea Warnick, 2012).

# Common Questions and Statements

I do not want to talk about cancer because it is so negative. I want my kids to enjoy being kids and not worry about my cancer.

Children are intuitive. They can tell when something has changed or if something is wrong. Not providing your children with this information may lead them to believe the worst-case scenario. It is always best for children to learn about cancer from a person they love and trust. This will ensure they receive the correct information in a supportive environment.

Most children can cope well with the right tools and support. Sharing your cancer diagnosis is the first step in ensuring your children can manage their worries in healthy ways.

My child learned about Terry Fox in school, and they know he died from his cancer. I am worried about telling them I have cancer because I do not want them to think that I will die too.

Many school-aged children have learned about cancer in the classroom already. They may have some basic understanding of cancer, and they may even associate cancer with death. But the good news is that many people have cancer and live! Children may overhear you on the phone or chat with a friend about your cancer, but if you share the news first, then they will be provided with the correct information and not left to wonder. The stories children make up are often much worse than reality. By telling your children the truth, they will feel safe asking questions and will trust that if things change, you will let them know.

Your children may ask, "are you going to die." Be prepared to answer that question honestly. You may say, "some people do die from their cancer, but lots of people do not. I am not dying." You may want to share positive news whenever possible "the doctors are giving me very strong medicine to help make the cancer go away. The doctors believe this medicine will help me and that I will recover. If anything changes, I will let you know." Children of all ages can be affected by your cancer diagnosis. It is important to provide children with a developmentally appropriate explanation of your cancer. You also do not need to discuss every detail about your cancer all at once. Each child is different; some children want lots of information, and some children only need a small amount of information to start. Several conversations over time typically support children best.

I am afraid I will be too upset to explain my cancer diagnosis to my children and this may make them feel more confused or scared.

It is important to have this conversation when you are feeling strong and supported. Be prepared and imagine how the conversation may go. It is best if this is a conversation with someone your child loves and trusts. However, sometimes it is difficult for parents to share this information. You may choose to have someone else share this information with you, being present as a support for your child. It is also okay to share your feelings with your children. You can let them know you are also feeling sad, worried, or scared. Model sharing your emotions with your children as this will encourage them to share their feelings with you too!

What if my child is not doing okay and needs more help?

Nankind has Certified Child Life Specialists to support you and your family throughout your entire cancer journey. Our Child Life Specialists are trained professionals whose role is to provide evidence-based and developmentally appropriate support and interventions to children.

Our goal is to ensure each child in our network is provided with the information, coping tools and play opportunities required to build resilience and thrive in the face of their parent's cancer journey.



# About Nankind

Our mission is to reduce the social and emotional impact of cancer on families. We believe no parent should have to choose between caring for themselves and supporting their children. Through our network of specially trained volunteers, we provide free childcare, child counselling, and support programs to parents facing cancer.

In-home Programs: Nankind Program for Children Virtual Programs: Homework Club, Fun-in-a-Box, Mom Support Group, Peer Support Group In-Office: Nankind Clubhouse, Kind Connections, Grief & Bereavement Support, Private Child life Consultations Additional Programs: Ronda Green Camp Program, Meal Program

Serves: Children 16 and under who have a parent with cancer including bereavement after the loss of a parent with cancer Registration: Call or email for enrollment Cost: Free

Office Hours: Monday to Friday 8:30 a.m. - 5:00 p.m. Address: 1000 Sheppard Ave West, Toronto, ON. Phone: 416-730-0025 Email: info@nankind.com Website: nankind.com

# Resources

#### **GILDA'S CLUB GREATER TORONTO**

Inclusive virtual programming of support, education and social interaction for the whole family – adults, children, and teens, as well as their family and friends. Note: Virtual support available across Ontario Email: info@gildasclubtoronto.org Phone Number: 416-214-9898 www.gildasclubtoronto.org

#### SHINE THROUGH THE RAIN

Helps families impacted by illness with financial guidance and support including a rainy day fund and camp scholarships. Email: info@shinethroughtherain.ca Phone Number: 905-477-7743 www.shinethroughtherain.ca

#### CHILDREN AND YOUTH GRIEF NETWORK

A network of grief support providers who provide resources and tools to support grieving children. Resources include e-courses, handbooks, and tip sheets. Email: info@childrenandyouthgriefnetwork.com www.childrenandyouthgriefnetwork.com

#### **211 ONTARIO**

Ontario 2-1-1 is a service that connects people to the support services needed in their local community Email: gethelp@211ontario.ca Phone: 211 www.211ontario.ca/search

#### WELLSPRING

Network of community-based charities offering free, referral-free programs and services to anyone with any cancer at any stage. Phone: 1 (416) 480-4440 www.wellspring.ca

# Books

#### A KIDS BOOK ABOUT CANCER

Storm, K., & Porter, S. (2020)

NOWHERE HAIR Glader, S. (2010)

THE INVISIBLE STRING Karst, P. (2000)

CANCER PARTY! Olsher, S. (2018)

WHEN SOMEONE YOU LOVE HAS DIED Seidler, S. (2022)

THE COLOR MONSTER Llenas, A. (2012)

HAVE YOU FILLED A BUCKET TODAY? McCloud, C. (2006)

THE HUGE BAG OF WORRIES Ironside, V. (2016)

# Your Notes

## nankind

### Get Help Today

| ¢,        | (416) 730-0025 (Ext. 2)                                     | f | ( |
|-----------|---|---|---|
| $\bowtie$ | info@nankind.com  | y | ( |
| •         | 1000 Sheppard Ave.<br>W., Suite 100, Toronto,<br>ON M3H 2T6 |   | ( |





Copyright © 2024 Nankind Inc. All Rights Reserved