



Moms' Cancer Conversation

A guide for talking to your children about cancer





INTRODUCTION

The Nanny Angel Network has developed Moms' Cancer Conversation so moms with cancer can speak with their children about their diagnosis in language they can understand. NAN's Moms' Cancer Conversation is designed as a guide, so that having this delicate conversation reduces anxieties and fears and provides clarity.

As a parent, protecting your child from any type of harm or sadness is paramount when talking about your cancer diagnosis. You may be worried about increasing your child's fears, saying the wrong thing, becoming emotional, or that your children won't understand. You are not alone. Research shows when children are not included in discussions about serious illness, they will react intuitively to changes in their routines and relationships. They may fill in the gaps in information on their own, and ask if they caused the illness, if they are at risk of catching it, and who will take care of them, should mom die.

This guide will give you the tools and language to start the cancer conversation with your children.



PREPARING TO TALK TO YOUR CHILDREN

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

1. 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), the shorter their attention span will be, so having a few phrases prepared and practicing them will help you communicate.
2. Plan to have the conversation in a familiar place, where your child feels safe and comfortable. This is most often at home. Check to 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.
 - Get on the same level as your child. If they like to sit on the floor, sit on the floor with them.
 - 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 well if it is available, and makes it easy to engage your child in the conversation.
3. Be open, honest, and tell the truth. This will make the conversation easier and relieve you of additional stress.
 - Practice saying the phrase, “I have cancer”. This is difficult and can feel overwhelming, but it is important to name your illness to educate and empower your children to talk about cancer.

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's 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 all of the information 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 their own ideas about what cancer is or have unreliable information. While they don't need a lot of detail about the illness, help them to name your cancer and understand where it is in your body.
4. Your children may each react differently, and that's 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 talking about their feelings or questions they have about your cancer, but remember they will most likely need an adult to take the lead.

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."

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 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 in nature. We don't know why it happens, but we have some medicine 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. It may be very scary, but this is normal.



IT'S NEVER TOO LATE TO HAVE THE CANCER CONVERSATION

There is no perfect time to talk to your children about cancer, but it's 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.

Remember to stay honest. Share your anxieties about sharing this information and be prepared to manage their anger or frustration in being excluded. It's 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.

INFANTS AND TODDLERS – UP TO 2 YEARS

Although babies have not yet developed enough to engage in conversation, they will be attune to changes in their routine and separation from you, their mother. 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 so that you can 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 have a tendency to construct their world in relation to themselves. It's important to give them the language to name your illness and reassure them that they did not cause your cancer, 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 that they are familiar with and a cancer diagnosis, and to establish and reassure them that they need not worry about catching the illness, in order to maintain physical bonds.

SIGNS TO WATCH FOR:

- 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 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 mortality, they may assume that all people who get cancer will die or believe unreliable information they learn about cancer from their classmates or friends.

It's 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.

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; 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.

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.

USEFUL PHRASES

"It can be scary to talk about cancer, and it scares me too, but it's 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."

"I will go to the doctor tomorrow and I will give you more information after that appointment."

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

SIGNS TO WATCH FOR:

- Your child may seem to be 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 towards other healthy caregivers.
- It's 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.

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's 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's 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's important that your teacher knows, so that you can talk to someone at school if you need to..."

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

TEENAGERS 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, 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's 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's 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's important that there is still structure in the home to support your children. This also applies to continuing to talk to your teenager about every day 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.

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 are:

1. A jar or shoebox
2. Strips of paper
3. Something to write with – a pen, pencil, crayon, or marker
4. Some string
5. 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 very helpful tool for your children at any age as they develop their emotion 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.

Feelings charts allow 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.

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

When you are facing end of life, we recommend the following when preparing to talk to your children.

1. Check in

- Let your child know that you need to update them on the progress of your cancer. Keep in mind the same tools that you did 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.

2. 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 end of life; however, it will be very important that you are able to be 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. It is crucial that your child understands 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 want 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 is able to ask questions if they have any along the way.

3. 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's important to address any fears or anxieties they might have that could cause them to avoid being involved.
- Include your children in funeral, celebration of life, or other end of life rituals that your family holds. It's important that they can contribute to this process so that they can continue to stay connected.

4. Legacy Work

- Some mothers will write letters or prepare special items to be given to their children at specific age milestones after her 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 it 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*).



RESOURCES

TORONTO

Gilda's Club

Address: 24 Cecil Street, Toronto, ON M5T 1N2

Telephone: (416) 214-9898

Email: info@gildasclubtoronto.org

Website: <https://gildasclubtoronto.org/>

Kids and Teens: <https://gildasclubtoronto.org/kids-and-teen-programs/>

Adult Programs: <https://gildasclubtoronto.org/adult-programs/>

Camp: <https://gildasclubtoronto.org/camp-in-the-city/>

Description: Gilda's Club's inclusive program of support, education and social interaction for the whole family – adults, children, and teens, as well as their family and friends – is offered in a home-like setting and provided FREE of charge to members. Gilda's members are given the tools and information they need to help them create their own support plan.

Serves: The kids program is for children aged 4-12, the teens program those aged 11-19.

Eligibility: Anyone experiencing bereavement after the loss of a loved one. Specific programs are dedicated set age groups, see program list for eligibility details.

Registration: Call or email for registration.

Cost: No cost.

Office hours: Monday to Thursday 9:00am to 8:00pm, Friday 9:00am to 5:00pm

Dr. Jay's Grief Centre

Address: 82 Lombard Street Suite 112 ,Toronto, ON M5C 2S8

Telephone: (416) 360-1111

Email: info@griefcentre.org

Website: <https://drjaychildrensgriefcentre.ca/>

Counselling: <https://drjaychildrensgriefcentre.ca/psychosocial-support/>

Resources: <https://drjaychildrensgriefcentre.ca/resources/>

Youth Program: <https://drjaychildrensgriefcentre.ca/youth-counselling/>

Description: The centre's main objectives are to provide counselling and psychosocial support to children who are dying, provide counselling to children who are experiencing the death of a family member, before, during, and after a loss. Facilitate educational and support-based groups for families and caregivers of grieving and terminally ill children.

Serves: Children 0- 12, Youth group 13-18.

Cost: No cost.

Accessibility: Located a short walk (less than 10 minutes) south from Queen Station. Use the TTC trip planner by clicking here: http://www.ttc.ca/Trip_planner/index.jsp

Contact for more information including registration.

PEEL

Heart House Hospice

Address: 855 Matheson Blvd. East Unit # 1, Mississauga, ON L4W 4L6

Telephone: (905) 712-8119

Email: info@hearthousehospice.com

Website: <https://hearthousehospice.com/>

Bereavement: <https://hearthousehospice.com/bereavement/>

Help Us Understand Grief (HUUG) Program: <https://hearthousehospice.com/huug/>

Hospice Counselling: <https://hearthousehospice.com/hospice-counselling/>

Description: The hospice counsellors, engagement coordinator, health and wellness coordinator, bereavement and spiritual care counsellor, and volunteers offer care and support for you and your family in your own home. Heart House Hospice cares for people with terminal illnesses and their families living in the Brampton and Mississauga communities.

Serves: Terminally ill patients and their families of all ages.

Eligibility: For people with terminal illnesses and their families living in the Brampton and Mississauga communities.

Registration: Call to get more information on ways Heart House can help you.

Cost: No Cost.

Accessibility: The offices are located at the south-west corner of Matheson Blvd. and Timberlea, West of Dixie Road and East of Hurontario. Entrance to the parking is from Timberlea.

Office hours: Monday to Friday 8:30am to 4:30pm

ONLINE

Telling Kids About Cancer: <http://www.tellingkidsaboutcancer.com/>

My Grief: <http://www.mygrief.ca/>

Kids Grieve II live webinar: <https://andreawarnick.com/webinars/>

Cancer Really Sucks (for teens): <https://cancerreallysucks.org/>

The Dougy Centre: National Centre for Grieving Children and Families (US)

Description: Resource for volunteers and families

Other Related Links and Information: Books/dvd resources, kids support FAQs, support in Spanish, guides for adults, tip sheets and more available online:

http://www.tdcbookstore.org/store/c1/Featured_Products.html

<http://www.dougy.org/grief-resources/>

BOOKS

Title: The Secret C: Straight Talking about Cancer

Author: Stokes, J. A.

Year: 2000

Title: Have You Filled a Bucket Today?: A Guide to Daily Happiness for Kids

Author: McCloud, C.

Year: 2006

Title: Lifetimes: A Beautiful Way to Explain Death to Children

Author: Mellonie, B.

Year: 1983

Title: Tear Soup: A Recipe for Healing After Loss

Author: Schweibert, P., & DeKlyen, C.

Year: 1999

Title: The Invisible String

Author: Karst, P.

Year: 2000

Title: When Dinosaurs Die: A Guide to Understanding Death

Author: Brown, L. K.

Year: 1996