

Talking with your children about a cancer diagnosis



THE
PETER GILGAN
CENTRE
FOR WOMEN'S
CANCERS



Canadian
Cancer
Society

TABLE OF CONTENTS

Introduction.....	3
The benefits of talking to children and/or teenagers.....	4
Choosing a time to tell children	5
Who should tell my children?.....	7
Where should I tell my children?.....	7
What is cancer?	9
How should I tell my children?	10
How your children may react to your diagnosis	12
Activities to help children cope.....	14
Recommended resources.....	16
Glossary.....	20
The Feelings Thermometer	21
Top 10 tips for talking with your children about your cancer diagnosis.....	22

Introduction

Talking about cancer can be overwhelming. This booklet was designed as a guide for you and your family. You may still be adjusting to the news of a cancer diagnosis and you may be concerned about causing your children distress. Your first reaction as a parent may be to protect your children by keeping information from them or by delaying the conversation. These feelings are normal and are very common.

However, keeping cancer a “secret” in the family is hard to do. Other families who have been through this tell us that there are many reasons why a simple and honest conversation with your children about cancer can help them feel and function better.

We hope that you find this booklet helpful. You may also wish to speak with your healthcare team as they can also support you with this effort.

CANCER IN DIFFERENT CULTURES

Culture plays a big part in how cancer is viewed and thought to be caused. It can also impact how and when cancer is discussed in a family, as well as who starts the conversation. There is no right or wrong way to discuss the news of a cancer diagnosis, as every individual and family is different.

TIP

The benefits of talking to children and/or teenagers:

- An honest conversation can create a safe and open family environment – bringing your family closer.^{1,2}
- Your family can help support one another throughout your cancer diagnosis.
- Children will feel a part of the discussion.
- Knowing gives your children permission to react, talk and ask questions about your cancer diagnosis.
- By telling your children and expressing your feelings – it shows them that it's okay for them to express their feelings.
- Hearing the news directly from you allows your children to get the most accurate information.
- Knowing what is happening and what the next steps are makes children feel more secure and less anxious.
- With good support, children often display resilience and can cope with a new reality.
- It allows you and your family to continue normal interactions, as much as possible.
- It shows that you trust your children.



1. Christ G.H., Christ A.E. (2006). *Current approaches to helping children cope with a parent's terminal illness*. C.A. Cancer J. Clin. 56(4):197-212.
2. Phillips F. (2014). *Adolescents living with a parent with advanced cancer: a review of the literature*. Psycho-Oncology 23(12):1323-39. doi: 10.1002/pon.3570. Epub 2014 Jun 9.

Choosing a time to tell children

It's understandable that you may want to delay talking to your children about your cancer diagnosis, at least until you feel you have all the information you need about the illness. However, most children can sense when something is wrong and may create their own explanations as to why their parents are distressed. It may be helpful to talk with your children soon after your diagnosis as the explanations they may create can be more distressing than the truth.

Some families choose to tell their children together and others choose to have one-on-one conversations. It may be helpful to tell your children within the same time period. Whether to tell them together or separately is your family's personal choice and you know your children best.

It may also be helpful to check-in regularly with them. Multiple conversations about your diagnosis and treatment will likely be required. If possible, provide information about future tests or procedures before they happen. This will allow your children to prepare and ask questions that are important to them.

THE RIGHT TIME TO TALK

Sharing the news right before bed or prior to an important event may prevent your children from processing the news or asking questions. It's important to choose a time when you can sit together as a family without interruptions.



Who should tell my children?

Discussing a diagnosis of cancer with your family can be very difficult. Even though it's a very hard thing to do, it's helpful for you to tell your child if you feel like you can.

Children are quite observant and even at very young ages, they can sense if something is different and suspect that something may be wrong. If you are unable to tell your child yourself, involving your partner, another family member or a friend who is close with your child are also good options.

"It's helpful for you to tell your child if you feel like you can."

Where should I tell my children?

- 1.** Find a space where you and your family are most comfortable.
- 2.** Ensure it's a time and place where you will not be interrupted.
- 3.** Sometimes finding that perfect place or time to sit down with the family can be intimidating. You may consider discussing the diagnosis with your children during a routine family activity (i.e. during a walk or sitting together on the couch).
- 4.** Remember, you are the expert when it comes to your family.

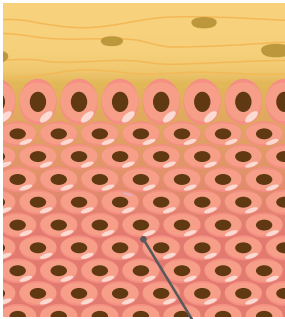


What is cancer?

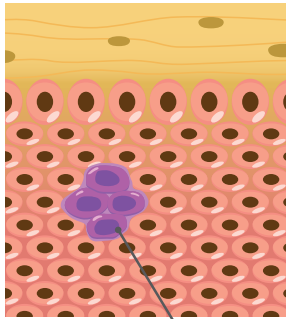
Our bodies are made up of millions of cells. Normal cells in the body follow instructions on how to grow, function, divide (form new cells) and eventually die.

Cancer occurs when cells do not follow these instructions and they continue to grow and divide in a way that is out of control. When this happens they can form a lump called a tumour, which disrupts the normal cells around it. Cancerous tumours can grow into (or invade) nearby tissues and spread (or metastasize) to other parts of the body.

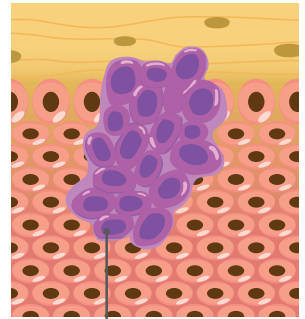
Growth of a Cancer Cell



Normal Cell



Tumour Cell



Malignant Cancer

WORDS TO USE

For examples of phrases to use in conversations, see the Canadian Cancer Society's 'Telling Children' resource on page 16, as well as the glossary on page 20.

How should I tell my children?

There are different ways to tell your children about your diagnosis, and a lot will depend on their age and developmental stage. In addition, children may need help with understanding medical terms for your illness or treatment.

- 1.** Consider practicing what you would like to say prior to speaking with your children. It may be helpful to try and anticipate some of their questions in advance, keep the conversation simple and use age-appropriate language.
- 2.** Don't be afraid to use the word cancer. Words such as "bad cells," or "the big C," can be confusing for children. You can start by encouraging your children to share what they already know about cancer to get an idea of their initial understanding of the disease. This may help clarify misconceptions and help them understand that cancers are not all the same.
- 3.** Make sure your children understand that it's not their fault, and that they did nothing to cause the cancer. Also, emphasize that they cannot "catch" the cancer and it cannot spread from one person to another.
- 4.** Tell your children what to expect next. Depending on their age, it may be helpful to explain the type(s) of treatment you will have, and how long it will last. This may include surgery, chemotherapy or radiation for example.
- 5.** Try to prepare your children ahead of time for any expected physical changes related to treatment, such as hair loss, weight change or fluctuations in energy levels. Explain that you will be receiving treatment to help you get better but at times there may be side effects to these treatments.
- 6.** Explore with your children how your cancer or treatment may affect their lives. Explain to them that at times their routines may be disrupted. Talk to them about who will look after them if you are unable to.

7. Allow your children time to process the information about your diagnosis and give them time to ask questions. Some children may not have a lot of questions initially – accept that they will talk when they are ready and try to answer questions as honestly as you can.
8. Ask your children how they feel about what you have told them and check-in often. Take the time to listen to their fears and concerns as it can help reduce their distress and support their coping.

Don't be afraid to say you don't know. Some questions may not have immediate answers.

IDENTIFYING PERSISTENT DISTRESS IN CHILDREN

Your child may feel upset after learning about a cancer diagnosis and may exhibit strong emotions and behavioural changes. If these behaviours persist for more than a few weeks, your child may need additional support to cope. Some signs that they may need additional support include:

- Persistent sadness or anger³
- Sleep disturbances (too much or too little)
- Changes in appetite
- Increased difficulty with schoolwork
- Changes in behaviour (e.g. acting younger than they are)
- Isolating themselves from their friends
- Stopping activities that they once enjoyed
- Trying to hurt himself or herself
- Risk taking behaviours (e.g. substance use or reckless driving)

Talk to your child's pediatrician or family doctor and/or your health care team to access additional resources.

3. The Canadian Cancer Society. (2016). *Children and Adolescents Coping with a Parent's Cancer. Guide for Families and Care Providers*. Montreal, Quebec: Quebec Division

How your children may react to your diagnosis

Depending on your child's age group, they will respond to your cancer diagnosis in different ways. Children can have many reactions. They may be scared or confused, angry or sad. Whatever they are feeling is okay and may change from day to day. Just like you, they too will have a wide range of feelings.

TODDLERS AND PRE-SCHOOL AGED CHILDREN

- May not understand what cancer is but have a basic understanding about illness or feeling sick.
- May feel confused, lonely, or scared.
- May worry that they caused the cancer.
- May miss the routine they are used to, and the amount of time and attention they normally get from you.
- May want to help make you feel better.
- May experience changes in behaviour such as irritability, sleep disturbances, bed-wetting, tantrums, or separation anxiety.
- May benefit from a close relationship with an individual who can maintain some of their daily routine.

SCHOOL-AGED

- May feel they did something to cause the cancer.⁴
- May struggle with talking about your cancer.
- May feel distress at not knowing how to ask about cancer and not want to upset you.
- May feel isolated from their peers who do not understand what is happening to your family.
- May experience changes in behaviour, increased anxiety, mood swings, and temper tantrums.
- May try to help you in a number of ways.

TEENAGERS

- May know what cancer is but may not have all of the correct information.
- May feel it's important to be included in receiving timely and honest information about your cancer.
- May feel isolated from peers who do not understand what may be happening to your family.
- May respond positively or negatively to having increased responsibility in the household.
- May struggle with talking about your illness or asking questions.
- May be at risk for depression or anxiety.

4. Ellis S.J., Wakefield C.E., Antill G., Burns M. & Patterson P. (2017). *Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions*. *European Journal of Cancer Care* (26), e12432, doi: 10.1111/ecc.12432.

EXTRA SUPPORT

Gilda's Club supports the whole family by offering support groups for children that run concurrently with adult support groups. For more information see page 18.

Activities to help children cope

NEWBORNS/INFANTS/TODDLERS (0-3)

- Give them a lot of hugs and kisses!
- Listen to relaxing music together.
- Try a gentle baby massage.

PRE-SCHOOL AGE (3-6)

- Read books together and use them as talking points.
- Ask your child to think of a time when they felt upset, angry, worried etc. Ask them to blow that feeling into a balloon or bubble and then pop it! Use this as a talking point for what can happen when we hold on to feelings for too long.
- Play doctor and locate the body parts affected by the illness. Use this as a way to talk about where you might need treatment or medicine.
- Use puppets or stuffed animals to act out various concepts/situations or do a puppet interview.
- Put on your favourite music and have a dance party!
- Use the “Emotions Thermometer” on page 21 to have a talk about feelings.

Guide your child by letting them know that holding the stone can help bring calm feelings.

- Use playdough or clay to create shapes using hands, trays or utensils. Add essential oil (lavender is soothing) to mix in with playdough.
- Feelings stones: Collect stones or buy them at a dollar store. You can decorate the stones and your children can use them to identify feelings, or to use as a self-soothing comfort object during difficult times.

PRIMARY SCHOOL AGE (6-12)

- Write stories or create a diary using a journal.
- Create a scrapbook using different materials and include things like handprints, family drawings (i.e. show your favourite things to do together as a family etc.)
- Outline a plan or schedule for the week/month. Make sure to include dedicated connected time, which can help create a sense of structure and routine during treatment.
- Create friendship bracelets or necklaces with bravery beads. Add one bead after each hospital visit, procedure or treatment. This will help your child feel that they are included in your care.
- Try expressive arts like tracing your bodies and labelling body parts that are affected by the illness and treatment. Your child may also want to express themselves using any type of imaginative art!
- Choose a plant that is easy to care for, that you and your child can easily manage together. Connect this activity to how we take care of something by making sure it gets what it needs to be healthy.

TEENAGERS (12-18)

- Create a video or audio recording of yourselves. Get creative!
- Practice stretching and doing yoga poses together.
- Take photographs and use photographs to identify feelings through the stories that they tell.
- Go grocery shopping and make a meal together.

Recommended Resources

ONLINE

PARENTS AND CAREGIVERS

Canadian Cancer Society – Telling Children

www.cancer.ca

Cancer Care – Helping Children Understand Cancer

cancercare.org

Canadian Association of Psychosocial Oncology (CAPO) – Start the Talk

www.startthetalk.ca

Wellspring – When a Parent Has Cancer

www.wellspring.ca

American Cancer Society – Helping Children When a Family Member Has Cancer: Dealing with Diagnosis

www.cancer.org

BC Cancer Agency – Children and the Family Websites

www.bccancer.bc.ca

Rethink Breast Cancer – Young Families + Breast Cancer

www.rethinkbreastcancer.com

Cancer Council – Talking to Kids About Cancer

www.cancer.org.au

CHILDREN AND TEENS

National Cancer Institute – When Your Parent Has Cancer

www.cancer.gov

Cancer Really Sucks (Designed for Teens by Teens)

www.cancerreallysucks.org

Rethink Breast Cancer – Kids' Guide

www.rethinkbreastcancer.com

MD Anderson Cancer Centre – Kid to Kid: Your Parent Has Cancer

www.youtube.com

Stop, Breathe and Think – Resources for Kids and Adults

www.stopbreathethink.com

BOOKS

Vanishing Cookies: Doing Okay When a Parent Has Cancer (1991), by Michelle Beth Goodman.

Where's Mom's Hair: A Family Journey Through Cancer (2005), by Debbie Walters and Sophie Hogan.

My Parent Has Cancer and It Really Sucks: Real-Life Advice from Real-Life Teens (2013), by Marc Silver and Maya Silver.

The Feelings Book (2005), by Todd Parr.

Mom Has Cancer! (2008), by Jennifer Moore-Mallinos and Marta Fabrega.

When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change (1996), by Marge Heegaard.

WOMEN'S COLLEGE HOSPITAL

SOCIAL WORK

The Social Worker will help individuals and families address and manage their emotional and social wellbeing. The Social Worker provides education and support to individuals and families throughout the cancer care experience and can help you:

- Cope with a diagnosis and process emotions from the cancer care experience.
- Develop coping mechanisms and build tools for self-care.
- Build on existing strengths and resiliency.
- Explore talking to children about a diagnosis or illness.
- Address and facilitate practical solutions for issues that affect day-to-day lives (e.g. transportation, finances).

Appointments: Held through face-to-face interactions, over the telephone or virtually through a computer or tablet.

Hours: Onsite support is available Monday to Friday, 8:30 am - 4:30 pm

Contact: 416-323-7330

STELLA'S PLAYROOM

A short-stay (max 2 hours) "play zone" for children to have fun and relax while their parents have appointments. Support includes supervision by early childhood educators for newborns to children up to 13 years old.

Hours: Monday to Friday, 9:00 am - 12:00 pm and 1:00 pm - 4:00 pm

Contact: 416-323-6400 ext. 3029

PEER SUPPORT AND INFORMATION SPECIALIST

Through personal experience and training, our peer support specialist can help you:

- Cope with the fear and anxiety from a breast cancer diagnosis.
- Better understand your diagnosis and treatment.
- Manage the challenges of living with breast cancer.
- Access community resources and services.

Hours: Onsite support available on Mondays from 9:00 am - 4:00 pm

Contact: 416-323-6274 or email: myccsupport@wchospital.ca

COMMUNITY

GILDA'S CLUB

A registered charity that provides emotional, social and practical support for anyone touched by cancer including men, women, teens, children, as well as family and friends. Gilda's Club offers:

- Support, information and networking groups
- Education
- Expert speakers
- Healthy life-style tips
- Art-based workshops
- Social and recreational activities

Membership and all programming are provided free of charge.

Contact: 416-214-9898 or visit: www.gildasclubtoronto.org

CANADIAN CANCER SOCIETY

A registered charity offering:

- Credible information
- Community resources (i.e. support groups, wig boutiques)
- Peer matching services
- A 'Wheels of Hope' transportation program
- Support and resources for caregivers
- A BRA (Breast Reconstruction Awareness) Day, to promote education awareness and access for women considering post-mastectomy breast reconstruction.

Contact: 1-888-939-3333 or visit: www.cancer.ca

WELLSPRING

A network of community-based support centres offering programs for:

- Peer support
- General support
- Rehabilitation
- Coping skills
- Expressive arts
- Education

Contact: 1-877-499-9904 or visit: www.wellspring.ca

NANNY ANGEL NETWORK (NAN)

A registered charity providing free and professional relief childcare for GTA-area mothers who have been diagnosed with cancer, including:

- Care for children 16 years old and under.
- Compassionate support for families throughout treatment, recovery, palliative care and bereavement.

Contact: 416-730-0025 or visit: www.nannyangelnetwork.com

Glossary

benign – non-cancerous

biopsy – removal of tissue with a needle or through surgery for further examination under a microscope

cancer – a group of diseases where abnormal cells divide and grow without stopping and invade the surrounding tissue

chemotherapy – medication usually administered intravenously (by I.V.) to kill cancer cells

fraction – a dose of radiation used in radiation treatment

invasive – cancer cells that have grown beyond the first layer of cells where they initially started developing

lymph node – small glands in many areas of the body that help the body filter out bacteria or cancer cells

malignant – another word for cancerous

metastasis – cancer cells that have spread from where they first started developing to other places in the body

pathologist – a doctor who diagnoses cancer or other types of disease by looking at cells under a microscope

primary location – the place in the body where cancer first started developing

radiation – cancer treatment using high-energy rays to damage or kill cancer cells, which can also be referred to as “radiotherapy”

reconstruction – surgery focused on rebuilding a part of the body

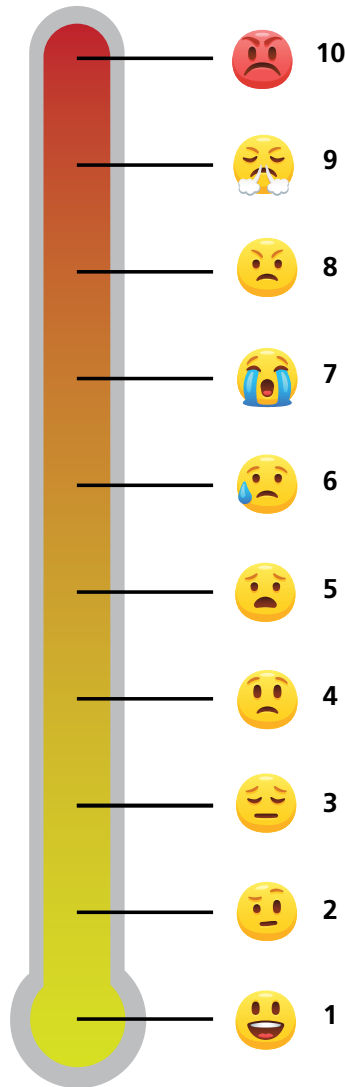
recurrence – cancer that has come back after it has been treated

stage – a system to describe the amount and progression of a tumour or cancer in the body, usually based on size, location, involvement of lymph nodes and whether or not it has spread to other parts of the body

tumour – the abnormal growth of cells that are either non-cancerous ‘benign’ or cancerous meaning ‘malignant’, that form a lump

The Feelings Thermometer

How do I feel today?



Children often have difficulty describing their feelings and the strength of them. The feelings thermometer can help children gauge the intensity of their feelings when dealing with stressful events.

TIP



Top 10 tips for talking with your children about your cancer diagnosis

- 1** Keep it simple: use age appropriate language
- 2** Identify the illness and the body part affected
- 3** Don't be afraid to say the word cancer
- 4** Be clear that no one caused the cancer and that it's not contagious
- 5** Explain how the cancer will be treated
- 6** Explore how your children's lives will be affected
- 7** It's okay to say "I don't know" and "let's ask"
- 8** Encourage your children to ask questions to share their feelings
- 9** Accept that your children will talk when they are ready
- 10** Check-in often with your children



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