

R.S. McLaughlin Durham Regional Cancer Centre

Talking with Children about Cancer

This booklet has information to help you as a parent living with cancer. This information may be useful for other adults in your family (for example a grandparent).

It can be hard to talk with your child about cancer. It may be upsetting for both you and your child. Every child is different and their reaction will be too. If you need more information or have concerns about how your child is coping, talk to a member of your healthcare team.

It may help you and your family to learn about:

- How to talk with your child about cancer
- How your child may react to your diagnosis
- The resources and supports in your community



Table of Contents

		Page
Questi	ons you may have	3
Age sp	pecific information	9
	Infants and toddlers (up to 2 years old)	9
	Preschool children (ages 3 to 5)	11
	School age children (ages 6 to 10)	13
	Preteens (age 11 to 13)	15
	Teenagers (age 14 to 18)	16
Examp	oles you can use to talk to your children	18
	Your cancer	18
	Your treatment	18
	Why you have cancer	. 19
	What may happen to you in the future	20
	Changes in your appearance and your activity	20
	Your child's feelings	20
Helpful	I supports in the community	21
Books		25
	Preschool and school aged children	25
	Teenagers	28
	Parents	29
Websit	tes	30
Videos	§	30
Campo		30

Questions you may have

Here is a list of common questions that other parents have asked.

1. Should I tell my child about cancer?

You know your child better than anyone else. It is up to you to decide when, how and what
to tell your child. Each family has to make this decision. Even a very young child knows
when there is something wrong and things are not normal.

Your child can see:

- Changes to their routine
- More family members and friends coming to visit
- People upset
- Whispered phone calls

Talking about cancer gives your child permission to talk about it too. Most children have active imaginations. When your child experiences change, they may use their active imagination to try and understand what is going on. These thoughts may worry your child more than the truth. If your child finds out about your cancer from someone else, the trust they have in you may be affected.

Your child may feel alone if they are not told about your cancer. They may feel they are not important enough to be included in something that affects your whole family. Being honest and open with your child may help your family become closer.

Dealing with cancer as a family can help your child learn about the body, cancer, treatment and healing. They can learn how to deal with difficult feelings. Adults often don't realize how well children can deal with the truth. Even hearing sad news is better than the worry they feel when they don't know what's happening. You can't stop your child from feeling sad. By sharing your feelings and giving your child information about what's happening, you can support your child if they are sad.

2. Who should tell my child?

- It is best for you to tell your child.
- If you don't feel you can tell your child, your partner or a close family member such as a grandparent, can tell your child for you. It's important you know what they tell your child. It may be helpful for you to be there for the talk.

3. When do I tell my child?

- It is usually best for your child to know about your cancer as soon as possible after your diagnosis.
- You can also talk with your child before you are diagnosed with cancer.
- If your child asks questions or seems worried about your health, talk with them again.
- Before you have a scan or treatment.
- When there are changes to your health or treatment.

You don't have to tell your child everything at once. You can give them small amounts of information at a time. Keep your answers short and stay on topic. Always check to see if your child understood what you told them.

If you have children of different ages, it can be helpful to tell them together and at the same time. This allows your children to hear the same information. They will also know that your cancer isn't a secret. You may need to give more information to your older children at a later time.

4. Is it okay for me to cry in front of my child?

• It's okay to cry when talking with your child about cancer. They shouldn't see hysteria or lengthy bouts of crying though. It's normal for your child to cry if they see you cry. Seeing you cry helps them to know it's okay to do this. If your child can't express their emotions, they may become frightened of their feelings instead of accepting them as normal. Crying together is a way of sharing feelings and supporting each other.



5. Where do I tell my child?

- There may be places where you and your child feel more comfortable talking together.
- Talk with your child when you know you won't be interrupted or rushed. Let your child know you have plenty of time to talk with them. For example, you may want to talk with your child at home on the weekend, when they don't have to go to school or other activities. Your child may ask questions when they are in the bathtub or before bedtime. Talking about difficult things at bedtime may make it hard for your child to go to sleep. It is important to make sure they feel comforted before they go to sleep.

6. What do I tell my child?

Start with the 4 C's:

Cancer: Say the word cancer. Using words like "the big C" or saying things like, "I have a bad seed growing inside" can be confusing to your child.

Cause: Tell your child that nothing they did or said caused your cancer. Nothing they do will make it worse or make it go away. Explain that you have doctors who have a plan to help you get better.

Contagious: Tell your child that cancer is not contagious and they (or anyone else) cannot catch it. Explain that it's a different kind of illness than a cold or chicken pox.

Care: Remind your child that they are loved and will always be cared for by the adults in their lives.

- Ask your child what they think cancer is. If they're not sure, explain it as well as you can. You may want to practice what you will say. Use words your child will understand. This booklet has some examples of what to say to your child about cancer. Don't be afraid to say, "I don't know" if you don't know the answer to a question. Some questions don't have answers. It is important to think about and plan answers for the questions you think your child may ask. Saying, "I don't know" all the time can cause your child to feel scared and unsure. Let your child know how their daily schedule will change. For example, if you have to go into the hospital, tell your child who will care for them.
- Talk about what will happen in the upcoming days or weeks. Ask your child if they are
 worried about anything. Listen closely to their answer. What your child says could be
 important in future talks. This booklet has some examples of what to say to your child about
 cancer treatment. Tell your child about any physical changes you might go through during
 treatment. Make sure your child knows that it's okay to talk and ask questions.

7. My child was having difficulties before my diagnosis. How do I talk with my child about cancer?

- If your child was having difficulties before your cancer diagnosis, they may need extra attention. If your child has a learning disability, they may need a different approach and support to help them understand what it means for you to have cancer. Talk to your child at a level they can understand. Pictures or stories can be useful. It may help to have your child write out their story. It can be sent to school and can be used with anyone who helps take care of your child. A story will make sure everyone is giving your child the same information. The story can be made into a little book that your child carries around.
- Your child may use alcohol or drugs to cope with your cancer diagnosis. If this was a
 problem before your cancer diagnosis, it may become more of a problem now. It can help
 to talk with your child about the changes you are seeing and support them in finding better
 ways to cope.
- If your child lives with any mental health challenges or behavioural difficulties, these problems may worsen when they find out you have cancer. It is important to talk with your child about any changes you see in their behaviour and get them the help they need.
- Children who have only one parent or live in a home where there are problems between the
 parents, have the same worries as children with two parents. They may have other worries too.
 If you are a single parent, your child may worry who will look after them if you are not able to. It
 is important for your child to know they will be looked after. It may help them to know who will
 care for them if you cannot.

There are a number of community organizations that offer supports that may be helpful to you and your child. They are listed in the back of this booklet.

8. What if my child asks if I will die?

Your child may have heard of cancer and know that people can die from it. If your child
asks you if you will die, it is important to tell them the truth. If your cancer is treatable, tell

- your child people rarely die from your kind of cancer. If you're not sure about your health, tell your child that you hope to get better and your doctors are doing the best job they can to make that happen.
- You may have been told you are not going to recover from your cancer. It is difficult to know that you are going to die. It will be hard for your child and family too. Many families don't talk about death and dying. You may feel uncomfortable talking about your death with your child. Many parents find this too painful. Talking about this openly as a family may help your child cope in the future. If you feel unable to talk about your death, you can ask a family member, a friend or a professional who knows you and your child, to talk with them. This person should be someone your child has trust in and has a good relationship with.
- Some parents write a letter to their child to be given to them at a later time. In a letter, you can tell your child more about your feelings and hopes for them. It may help to know that you are leaving a message of love for your child. Other parents find it helpful to make a memory box or scrapbook. These activities can be both helpful and hard for you to do.

9. How do I know if my child is having problems coping?

- It's normal for your child's feelings and behaviour to change for a few weeks after they hear you have cancer. During this time, it is important to comfort your child. Let your child know it is okay to have many different feelings. Talk with your child's caregivers (for example daycare staff, teacher or babysitter). They will be able to tell you about your child's behaviour when you're not around.
- If changes last longer than a few weeks, your child may be having problems coping. Some signs include:
 - Your child who is normally quiet starts to misbehave and argue.
 - Your child who is normally concerned about himself/herself, starts taking care of everyone in the family.
 - Your child who is normally friendly becomes moody, quiet, fearful or anxious.
 - Your child starts acting younger than they are and continues with this behaviour for a month or more.
 - Your child has trouble sleeping (too much or too little sleep or nightmares, sleep walking, fear of falling asleep) for a month or more.
 - Your child has changes in their eating habits (eating too much or too little) for a month or more.
 - Your child is having more trouble than normal with schoolwork.
 - Your child no longer wants to do normal activities like sports or playing with friends.
 - Your child attempts or threatens to physically hurt themselves. It is not okay for your child to feel this way. You should get help right away. Take your child to the emergency department at the hospital closest to you. Ask to talk to a youth crisis team or a psychiatrist.

10. Where can I get help for my child?

- Remember you know your child best. If your child is responding in a manner you are not sure is normal, start by asking yourself, "How has my child responded to difficulties in the past?" Their response may not be that different from their usual response. If you feel there is something wrong, talk to a member of your healthcare team. This will allow you to get the help your child may need.
- Your healthcare team can make a referral for you to talk to someone who has specialized training in counselling. You may want to go for counselling alone, or with your whole family. Social workers are available at the cancer centre or at any hospital where you have your cancer treatment. Social workers are also available through the Central East Local Health Integration Network (LHIN): Home and Community Care Program. They can come to your home to talk with you or your family.

A social worker may help if you:

- Would like to practice talking with your child
- Need help telling your child
- ➤ Have concerns about how your child is managing at home or school
- Would like to know more about community resources

Hearth Place Cancer Support Centre offers individual and group sessions for children who are coping with the illness or loss of a loved one to cancer. Child life specialists and play therapists help children navigate their feelings using age appropriate language and effective strategies. A Kids Care Package containing: this booklet, an activity book to share with your child and a stuffed animal, is available for you to have for you and your child. Emotional support, wellness classes and information workshops are also available for adults.

Your family doctor may be a good support for you and your child, especially if they know your child well. They can assess your child and refer you to the right person or organization.

Employee Assistance Programs (EAP) can be accessed if you or your partner has benefits through work. EAP have social workers or psychologists who offer short-term counselling or crisis support. The support from this program is kept confidential. No information will be shared with your employer. Counselling is for individuals, couples or families. Call the human resources department at your place of work or talk to the person who handles your benefits.

School and day care staff (this might include your child's teacher, guidance counsellor, school social worker or day care provider) can be helpful in noticing changes in your child's behavioural and emotional responses. Even if your child does not seem to be having a hard time, it is helpful to tell the staff about your cancer diagnosis and what your child is experiencing at home. They can tell you about any changes or concerns, or offer comfort and support to your child during difficult times. It can be helpful to talk with the staff regularly to make sure your child is doing okay. You can talk to them about getting extra support. Guidance counsellors and social workers are available at most schools. Many high schools have trained facilitators who lead coping and bereavement support groups for teens. You may also want to talk with other patients who have cancer and ask them what worked for their family.

Ask a close friend or family member for help, especially if you are feeling ill, overwhelmed or exhausted. Ask them to call some of the community resources listed in this booklet.

11. How can I help other children understand?

- Other children and their families may talk about you and your health. You may want to help them understand what is happening. It is important to talk with your child. They may not want others to know that you have cancer.
- Let your child know you are willing to talk to their friends if they want you to.

12. How do I discipline my child during this difficult time?

You may find it hard to have rules or to discipline your child. Your child may behave badly
to get your attention. Even though you have cancer, it is important to discipline your child
as you normally would. Let your child know that bad behaviour will not be allowed. Praise
their good behaviour.

13. How do I involve my child in my care?

- Your child may be able to help with your care. This can help your child feel included and special. Your child can help by bringing you a drink or snack, the paper or a book to read.
- Make sure your child has enough free time. Your child will likely remember what you do with them, more than how much time you spend with them. As much as possible, plan your days so you can share special events with your child. If you have to miss an event your child participates in, have it recorded and watch it with your child at home. There are many activities you can do together that don't need much energy reading, watching TV or movies, drawing or writing a story. Have play dough and other creative materials on hand.



14. What do I tell my child if I have to stay at the hospital?

- Be open and honest with your child about why you are in the hospital. Tell your child about the procedures or tests you will have. This can help them feel more comfortable about you staying in the hospital. Before your child visits you in the hospital, it is important to prepare them for what they might see and experience. It can be helpful to explain how the hospital bed and the call button works, how your meals will come and who will be involved in your care.
- Members of your healthcare team, including the hospital social worker, can help answer any questions you and your family have.
- Ask the hospital staff about children's play rooms or other areas your family can use.

• When your child is away from you, have them call you on the phone, use face-time or skype, or exchange pictures or gifts. Your child may want to pick out a favourite picture of himself/herself for you to take to the hospital. You can give your child a picture of you to keep with them. Use creative ways to stay in touch, such as: drawing pictures, using a calendar to count down the days until you come home, or making a sign for your homecoming.

Age specific information to consider when talking with your child

Your child may have special needs because of their age, development or maturity. The information below will help you talk to your child about your cancer.



Infants and toddlers (up to 2 years old)

Children in this age group:

- Are focused on themselves
- Understand things by what they see and can't always understand what you explain to them
- Know when something is wrong with you
- Know when something is gone, but they can't understand the idea that it can come back
- May act out in protest or sadness when you aren't around hoping you come back
- Are starting to understand simple words like 'hurt', 'boo-boo,' or 'sad'
- Do not understand ideas like 'yesterday' and 'tomorrow'
- Depend on you to keep them safe and feel loved
- May take time to get used to changes with you or their surroundings

What may be scary or upsetting for your child

- Being separated from you
- Not feeling comforted or safe
- Sudden changes to their regular daily schedules
- Someone else's needs being put before theirs

What you can do to help your child cope

 Use simple language to talk to your child. Although they will not understand what it means to have cancer, it is good to use the word 'cancer'. Pair the word 'cancer' with other words you use when you have something that hurts (for example 'boo-boo') so that your child will understand you are sick.

- Give your child lots of hugs, cuddles or kisses. Your child feels comfort when you are close.
- If you are in the hospital, encourage your child to come for short visits, especially when they are ready for a bottle or quiet story. Talk to your child and assure them you are coming home from hospital soon (if true) and you think of them when you are not together. Remember to have someone bring food and toys for your child when they visit.
- Keep a regular daily schedule for your child (as much as possible).
- Use the same caregiver for your child (as much as possible).
- If your child comes with you to appointments, bring food and toys.
- Give your child a T-shirt or scarf that has your scent on it. This can help comfort them when you are not with them.



Preschool children (ages 3 to 5)

Children in this age group:

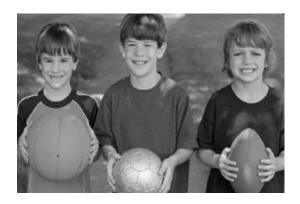
- Are focused on themselves and you
- · May ask for you or repeatedly ask where you are and why, or what you are doing
- May feel like you have abandoned them and become angry
- You may find your child attaches himself/herself to a substitute parent
- Know when something is wrong with you
- Can understand simple words like 'hurt', 'boo-boo', or 'sad'
- Are starting to understand ideas like 'yesterday' and 'tomorrow'
- Are starting to understand simple ideas about how the body works
- Will pay attention to what you are saying for a short time
- May become active or return to play quickly after you talk to them
- May use play to help make sense of their world and express their feelings
- May regress or return to a less developed behaviour. For example, if your child was potty
 trained they may begin to wet the bed again or if your child no longer sucks their thumb they
 may begin to do so again. Regression is often a response to changes in routine. It is usually
 temporary and will likely change back as your child adjusts.

What may be scary or upsetting for your child

- How their own life has changed
- Believing they caused your cancer or they have the power to change it
- Thinking they can catch cancer, like a cold or chicken pox
- The physical changes they see in you (your hair loss or loss of a body part)
- What other children think, say or do about how different you look
- New and different places, like the hospital

What you can do to help your child

- Talk to your child in a way they understand what you are telling them. Although they may not
 understand what it means to have cancer, it is good to use the word 'cancer'. Pair the
 word 'cancer' with other words you use when you have something that hurts (for example 'booboo') so that your child will understand that you are sick.
- Your child won't understand long words or medical terms. Your child may know a word like tummy, heart, breast or brain. They are less likely to know unfamiliar words like colon or ovary.
- Show your child where the cancer is on your body. You may want to use a picture and put a band aid on the body part that has cancer.
- Tell your child again and again they did not cause your cancer. They have not done, said or thought anything that could have caused your cancer. Explain to your child that they cannot do anything to change it.
- Explain to your child that cancer is not contagious (cannot be caught) and cannot be passed to someone else like a cold or the chicken pox.
- Be available to answer questions and talk at any time.
- Keep a regular daily schedule (as much as possible). Tell your child about changes in their schedule for the day (each day or the next day).
- Give your child lots of hugs, cuddles, or kisses.
- If you are in the hospital, encourage your child to come for short visits. It's a good idea to let
 your child run around outdoors first, so they are calm during the visit. Remember to have
 someone bring food and toys for your child when they visit.
- Pretend play can help your child learn and understand what's happening. Give your child toys like dolls, puppets, doctor's kits or a toy ambulance they can use during pretend play.
- If your child comes with you to appointments, bring food and toys.
- Reassure your child you are still their parent. Letting your child know there are still rules is important during stressful times.
- Read books with your child that relate to your cancer and treatment or similar stories about animals, hospitals, doctors and nurses.
- Watching your child react to your cancer diagnosis by regressing can be upsetting. Talk with your child about their behaviour. Be patient and work through it with them. Encourage your child to return to the more advanced behaviour they had before. Spend extra time with your child. You may want to have some quiet time before bed or do a small activity together. If the regressive behaviour continues, you may choose to seek help.



School age children (ages 6 to 10)

Children in this age group:

- Depend on you and need your attention
- Want to fit in with their friends
- Can understand ideas like 'past', 'present' and 'tomorrow'. They don't understand ideas about the 'future'
- Are starting to use reason and common sense in their thinking
- Are concerned about rules and fairness
- Are interested in how different parts of the body work
- Use play and creative arts to make sense of their world and express their feelings
- Will quickly return to play, pretend and distraction when they have heard enough
- Are more aware of their feelings and why they have them
- Learn quickly and use what's learned to find more information
- May have many 'why?' questions which can be difficult to answer
- May understand treatment helps you get well
- May have heard of 'cancer' at school (for example from Terry Fox Day) and may think of cancer as leading to death

What may be scary or upsetting for your child

- Thinking you will die
- Thinking their healthy parent will get sick too
- Believing they caused your cancer or they have the power to change it
- Thinking they can catch cancer, like a cold or chicken pox
- How their own life has changed
- Not knowing what will happen next
- Not knowing who will look after them
- Mistaken ideas about cancer because of things they heard from friends or saw on TV
- What their friends will do, say or think about how different you look

What you can do to help your child

 Be clear and talk simply to your child. Use the word cancer. Explain your cancer diagnosis, treatment and any medical equipment you need.

- Show your child where your cancer is on your body. Make sure you give them the right information in case they have mistaken ideas. Let your child know it is all right to ask questions.
- Provide lots of time for your child to talk or ask questions. Don't be surprised if your child doesn't want to talk when you do. Be prepared to just 'be' together.
- Don't take it personally if your child seems more interested in your medical equipment or your surgery scar rather than how you feel.
- Tell your child again and again that they didn't cause your cancer. They have not done, said or thought anything that could have caused your cancer. They cannot do anything to change it. Your child may believe they have already "figured out" why you got cancer, and have come up with an answer that shows their young thinking. It can be helpful to explore this a little further with them.
- Explain to your child that cancer is not contagious (cannot be caught) and cannot be passed to someone else, like a cold or the chicken pox.
- Keep a regular daily schedule (as much as possible). Tell your child about any changes in their schedule for the day or the current week.
- Give your child lots of hugs, cuddles or kisses. Your child may feel lonely and worried. Being near and reassuring your child can help.
- Let your child feel angry. It's a natural part of adjusting to your cancer diagnosis.
- Reassure your child you are still their parent. Letting your child know there are still rules is important during stressful times.
- If you are in the hospital, plan things you and your child can do together like watching a video, reading a book, or playing a board game.
- Read books with your child that relate to your cancer and treatment or similar stories about animals, hospitals, doctors and nurses.
- Pretend play can help your child learn and understand what's happening. It is important to support this. Give your child toys like dolls, puppets, and doctor's kits or a toy ambulance that they can use during pretend play.
- Be patient and understanding if your child seems selfish about how your cancer is affecting them. Remember your child doesn't know how to look at things any other way.
- Recognize the scrapes and bruises your child gets are still significant events in their life.
 Reassure your child they are not life threatening injuries and are different than cancer.



Preteens (ages 11 to 13)

Children in this age group:

- Have important relationships outside of their family. Their friends are very important to them.
- Need facts to help them understand information they are given.
- Are beginning to think abstractly. This means they can use facts to create their own ideas or meanings of things.
- Want more freedom but may struggle to be responsible.
- Use play and creative arts to make sense of their world and express their feelings.
- May be self-centred. Their ideas and thoughts are often about how things will affect them.
- May show frustration to cover-up their real feelings.

What may be scary or upsetting for your pre-teen

- Thinking you will die
- Thinking their healthy parent will get sick too
- How their own life has changed
- How your cancer will affect their social life
- Not knowing what will happen next
- Mistaken ideas about cancer because of things they have heard from friends or seen on TV

What you can do to help your pre-teen cope

- Be clear and talk simply to your child. Use the word cancer. Explain your cancer diagnosis, treatment and any medical equipment you need. Make sure you give your child the right information in case they have mistaken ideas.
- Tell your child again and again they didn't cause your cancer. They have not done, said or thought anything that caused your cancer. They cannot do anything to change it.
- Let your child know they should continue their regular activities. Encourage your child to keep their relationships with friends and other important adults in their life.
- Let your child feel angry. It's a natural part of adjusting to your cancer diagnosis.
- Reassure your child you are still their parent. Letting your child know there are still rules is important during stressful times.
- Give your child some added tasks without overloading them. They are not a parent and should not take on full parental responsibilities. Focus on tasks that apply to them (for example, making their own lunch).
- Keep a regular daily schedule (as much as possible). Tell your child about what will happen during the next few days or weeks, even if they don't seem interested. Your child should learn the facts from you, not from other people.
- Your child may let school work slip. Although this is normal, it's important to get your child back on track and encourage them to work hard at school.
- Provide lots of time for your child to talk or ask questions. Don't be surprised if they don't want to talk when you do. Be prepared to just 'be' together.
- If you are in the hospital, plan things you and your child can do together like watching a video, reading a book, or playing a board game.
- Regularly ask questions to check your child has the right information about your cancer.
 If they don't, make sure you give it to them.

• Be patient and understanding. Your preteen child needs time to cope.



Teenagers (ages 14 to 18)

Children in this age group:

- Want to be independent, but they still need you. Your teen may want to do things on their own while still trying to stay close to you.
- Have friends that are as important as their family.
- Can understand complicated information about cancer. They can likely handle medical terminology with a brief explanation of what it means.
- Think abstractly. They may have some understanding of abstract concepts like life and death.
- Care about what their friends think. What their friends think can influence what your teen does.
- Have an increase in their hormones that can cause them to have mood swings.
- May talk about their feelings in more detail.
- May feel as if the whole world is looking at and judging them.
- May seem mature, and other times behave as if they are much younger.

Your son may have difficulty dealing with women's cancers, such as breast, cervical, or ovarian due to self-consciousness around the time of puberty. Your daughter may worry she will develop the same type of cancer.

Your daughter may have difficulty dealing with men's cancers, such as prostate, testicular or penile cancer due to self-consciousness around the time of puberty. Your son may worry he may develop the same type of cancer.

What may be scary or upsetting for your child

- Thinking you will die
- Not knowing what will happen in the future
- How their own life has changed
- That their friends will reject them
- Whether they are ready to be an adult
- When their life feels like it is out of control
- Feeling alone and misunderstood
- Mistaken ideas about cancer because of things they heard from friends or saw on TV

What you can do to help your child cope

- Give your child lots of information about your cancer. Use the word cancer. Encourage your child to ask questions and tell them about changes to your health. Don't be surprised if your honesty is met by silence and closed body language or one-word answers from your child. They may seem irritated or angry and storm out of the room. Your child may need to be alone. Don't push your child to stay and listen. Let your child know you are available to talk.
- Your child may have a very hard time. Your child's emotions are sometimes complicated and troublesome. Acknowledge their differing emotions, such as anger, frustration or sadness. Let your child feel angry. It's a natural part of adjusting to your cancer diagnosis.
- Reassure your child that you are still their parent. Be consistent with rules when responding to problem behaviours.
- Be realistic about how much time you expect your child to be at home. Be specific about what
 your child can do to help. Allow your child to express what they feel would be realistic and be
 involved in the planning. Don't give your child too much responsibility, even if they are willing
 to take it on. They are not a parent and should not take on full parental responsibilities.
- Don't take it personally if your child seems more interested in their friends and social life. Friends are your child's support system. Encourage them to be with friends.
- Don't expect your child to become an adult overnight. Allow them to be a teenager.
- Encourage your child to use a journal or sketchbook to privately express their feelings, especially if they have a hard time talking. Art classes and writing clubs can be helpful at this time.
- It may help to reassure your child that talking about their feelings and worries is a positive way of coping and is how adults often deal with stressful situations. Encourage your child to talk to another trusted adult. It may be easier for your child to talk to an aunt, uncle or favourite teacher rather than you.
- Your child may want to know how your cancer will affect them. "Will it get in the way of their social life?" "Will they have to do more chores?" This is normal. Be honest with your child.
- In an attempt to understand your cancer diagnosis, your child may want more information. You
 can ask your healthcare team for more information to share with your child. Ask your child if
 they want to come with you to your appointments. This can help them understand what you're
 going through.
- There will be some questions you don't know the answer to because you cannot predict the future. Be honest with your child when you don't know the answer. Admit you don't know.
 Tell them what you do know.
- Your child likely understands cancer can be a life-threatening illness and have some understanding of abstract concepts like death. Your child may ask you if you will die from cancer. If they don't ask, it is safe to assume that they are wondering. Share what you know about your prognosis with your child. If you have been told your cancer is curable, you will be able to honestly say the doctors believe you will be cured. If you have been told your cancer will not likely be cured, tell your child this. It is important, but can be challenging for your child to have a balance between having hope and being realistic. Explain what the goals of your treatment are.
- Your child may let school work slip. Although this is normal, it's important to get your child back on track and encourage them to work hard at school.



Examples you can use to talk to your child about:

Your cancer

- "I am sick."
- "I may look okay, but I am sick."
- "I have a sickness (disease) called cancer."
- "I am sick. I have a 'boo-boo' called cancer. It grew in my body but isn't supposed to be there."
- "The cancer is in my stomach, right here" (point to picture or body area) or "My cancer started in my breast (point to picture or body area) and spread to my lung" (point to picture or body area).
- "There is something in my body that shouldn't be there. It is called cancer. It is making me feel sick. It's not like when you fall or hurt your knee, or when you get a cold. It's something that makes your body get hurt on the inside."
- "I have an illness. It's called cancer. The doctor is giving me treatment to help me get well. Sometimes I will feel ill or tired and sometimes I will feel fine."
- "Some of the cells in my body are growing too quickly and have made a lump. It is called cancer. The doctors will take the cancer out during an operation."
- "A lump was growing in my body that wasn't supposed to be there. It is called cancer. The
 doctors took it out in an operation. Now I will have treatment so that it doesn't come back. If
 you have any questions about cancer, you can ask me. Sometimes you may hear frightening
 things about cancer, but there are lots of different types of cancer. I will tell you what we know
 about my cancer."
- "Cancer is not something you can get (catch) from me. I can't give it to anyone."
- "The cancer is trying to grow again. That makes me angry and sad too. I have to take
 treatment to try to get rid of it. The doctors know a lot about taking care of people when this
 happens. They think this treatment will help me."

Your treatment

• "I am getting some medicine to help me get better. The medicine is called chemotherapy. It kills the cancer little by little."

- "Chemotherapy is medicine that can be given as a pill, an injection or through an intravenous line. It destroys cancer cells."
- "The radiation goes into my body and kills the cancer. I will have some purple marks on my skin to show where to point the machine so that the radiation kills the cancer."
- "I have to have radiation treatment. Radiation uses high-energy rays to kill cancer cells and shrink tumors."
- "I have to go to the hospital. A hospital is a place where people go when they are very sick. There are doctors there who try and help people feel better."
- "The treatment might make me look and feel even sicker than I did before starting the treatment. That's what happens so I can get better."
- "The doctors don't think I am going to get better. I am going to get some treatment that will hopefully slow the cancer down so I can live for a few months longer."

Why you have cancer

- "Nobody really knows why I got cancer. It just happened. I didn't want to get cancer and nobody made me get it."
- "We don't know why I got sick (cancer). What we do know is it's not anyone's fault. It's not my fault or your fault. It is not punishment for doing anything wrong. Some things in life are a mystery and we don't know the answers to them."
- "You had nothing to do with me getting sick. Nothing you said, did or thought made me get cancer."
- "It is no one's fault. Nothing you did or said made me ill."
- "Although you are in the same family you are your own person. You are different from me.
 You are healthy and will probably live for a long time."
- "You cannot catch cancer. Most people die when they are old and their bodies get worn out. It
 is unusual and sad for someone young to be so sick that the doctors cannot make them
 better."

What may happen to you in the future

- "I should be finished chemotherapy after your birthday or the summer (or any big event)."
- "I have to have chemotherapy until around the time when school is finished and summer vacation starts. Then I'll go to the doctor to see how it has worked."
- "Right now the doctors expect I will be fine. With the type of cancer I have, the medicine usually kills the cancer."
- "Nobody is sure right now if they can make the cancer go away, we all need to hope (pray) that what they are trying will work."
- "Even if your worst fears (and mine) happened and I died, you would be taken care of. You
 would continue to get lots of love from the rest of our family and friends and you would feel my
 love for the rest of your life."
- "I'm not dying now. We are expecting the treatment to get me well again. I promise to tell you
 if the doctor thinks treatment isn't working and I'm getting worse. Let's think about how we will
 get through treatment and have the best time we can together."

Changes in your appearance and your activity

- "My hair might fall out. It will grow back in after I finish getting the medicine (chemotherapy)."
- "I know I look different on the outside but on the inside I'm the same and I love you. Maybe you could put a picture of me beside your bed so you remember how I usually look."
- "It may be a long time before I can do the things with you I usually do. Although my hair will grow back and I will look the same, I will probably still feel tired for a long time."

Your child's feelings

- "If you have any questions at all, please ask me. I don't want you worrying about this all by yourself. We need to talk about things and be open with each other."
- "Being ill makes me feel sad. It's all right for you to feel sad (or angry or happy or whatever emotion). Our feelings change but I will always love you."
- "You can play and be with your friends and do what you usually do. I don't want you to be sad and sit around all day."

Your cancer diagnosis and treatment can be difficult but may have some positive effects. You may be spending more time with your child and actually feel closer to them. Sharing your emotions can strengthen the bond between you and your child.

Your child may grow in their ability to face other difficult life experiences. They can grow in independence and self-confidence. Your child may become more responsible. They may become more sensitive to the needs of others and more able to understand and love another person. You can take pride in your child's ability to deal with problems and find new solutions.



Helpful supports in the community

1. **Cancer Support Centres** give you and your family members support and help you find new ways to care for yourself and each other.

Organization	Address	Phone Number	Website
Hearth Place Cancer Support Centre (Durham)	86 Colborne St., W., Oshawa	905-579-4833	www.hearthplace.org
Wellspring Cancer Support Network (Toronto)	4 Charles St., E., Suite 400, Toronto	416-961-1928	www.wellspring.ca/downtown-toronto
Gilda's Club (Greater Toronto)	24 Cecil St., Toronto	416-214-9898	www.gildasclubtoronto.org

2. **Counselling** helps people sort out their problems. It is a place you can go to talk about your feelings. You can go by yourself or with a family member or friend.

Organization	Address	Phone Number	Website
Family Services Durham	605 Rossland Road E., Whitby	905-666-6240	www.familyserviceontario.org
Catholic Family Services Durham	117 King St., E., East Wing, 2 nd floor, Oshawa	905-725-3513	www.cfsdurham.com
Oshawa Psychological and Counselling Services	117 King St. E., East Wing, 2 nd floor, Oshawa	905-721-7723	www.oshawapsychologist.com
Community Counselling Centre Northumberland	1158 Division Street, Cobourg	905-372-6318	www.northumberlandccc.com
Community Counselling and Resource Centre (Peterborough)	459 Reid St., Peterborough	705-742-4258	www.ccrc-ptbo.com
Scarborough Centre for Healthy Communities	4100 Lawrence Ave E., Scarborough	416-642-9445	www.schcontario.ca

3. **Children's Mental Health Agencies** assess and treat children and youth under age 18 facing emotional and behavioural issues.

Organization	Address	Phone Number	Website
Frontenac Youth Services (Durham)	1160 Simcoe St., Oshawa	1-888-454-6275 (intake)	www.frontenacyouthservices.org
CAREA Community Health Centre	115 Grassmere Ave., Oshawa 1450 Kingston Rd. #17, Pickering 1615 Dundas St. E., Suite 211, Whitby	905-723-0036 extension 3200	www.careahc.ca
Kinark Child and Family Services (Durham)	20 Sunray St., Whitby	1-888-454-6275 (intake)	www.kinark.on.ca
Kinark Child and Family Services (Northumberland)	20 Strathy Rd, Unit 3, Cobourg	1-888-454-6275 (intake)	www.kinark.on.ca
CHIMO Youth and Family Services (Haliburton and Kawartha Lakes)	107 Lindsay St. S., Lindsay	1-888-454-6275 (intake)	www.chimoyouth.ca
Kinark Child and Family Services (Peterborough)	380 Armour Rd., Suite 275, Peterborough	1-888-454-6275 (intake)	www.kinark.on.ca
Peterborough Youth Services	459 Reid S., Peterborough	705-743-1681	www.pysonline.ca
East Metro Youth Services (Scarborough)	1200 Markham Rd., Scarborough	416-438-3697	www.emys.on.ca
Aisling Discoveries Child and Family Centre (Scarborough)	325 Milner Ave, Suite 110, Scarborough	416-321-5464	www.aislingdiscoveries.on.ca

4. **Community Health Centres** have programs to help you and your family members stay healthy.

Organization	Address	Phone Number	Website
Oshawa Community Health Centre (Durham)	115 Grassmere Ave., Oshawa	905-723-0036	www.ochc.ca
Port Hope Community Health Centre (Northumberland)	99 Toronto Rd., Port Hope	905-885-2626	www.porthopechc.ca
Kawartha Lakes Community Health Centre	108 Angeline Street., S., Lindsay	705-324-7323	www.ccckl.ca
Haliburton Highlands Family Health Team	7217 Gelert Rd., Haliburton	705-455-9220	www.hhfht.com
Peterborough Public Health	185 King St. E., #304, Peterborough	705-743-1000	www.pcchu.ca
Trent Hills Family Health Team (Campbellford)	119 Isabella St., Campbellford	705-653-1801	www.thfht.com
Taibu Community Health Centre (Scarborough)	27 Tapscott Rd., Unit 1, Scarborough	416-644-3536	www.taibuchc.com
Scarborough Centre for Healthy Communities – Community Health Centre	2660 Eglington Ave E., Scarborough	416-847-4101	www.schcontario.ca

5. **Hospices** have trained volunteers that can give support to you and your family members as you live with a serious illness.

Organization	Address	Phone Number	Website
VON Durham Hospice	1615 Dundas St., E., #304, Whitby	905-240-4522	www.durhamhospice.org
Community Care Northumberland Hospice	1005 Elgin St., W., Suite 203, Cobourg	905-372-7356	www.commcare.ca

Organization	Address	Phone Number	Website
Haliburton	7199 Gelert Rd,	705-457-2941	www.hhhs.on.ca/community-
Highlands Health Services	P.O. Box 115, Haliburton	Extension: 2932	support-services/hospice
Community Care City of Kawartha Lakes – Hospice Services	2 Kent St. W., Lindsay	705-324-7323	www.ccckl.ca/services/hospice
Hospice Peterborough	325 London St. Peterborough	705-742-4042	www.hospicepeterborough.org
Scarborough Centre for Healthy Communities Hospice – Hospice and Palliative Care	2660 Eglinton Ave E., Scarborough	416-642-9445 Extension: 4419	www.schcontario.ca

6. **Municipal Offices** connect you to community, social, health and government services in your region.

Organization	Address	Phone Number	Website
The Region of Durham	605 Rossland Rd., E., Whitby	905-668-7711	www.durham.ca
The County of Northumberland	555 Courthouse Rd., Cobourg	905-372-3329	www.northumberlandcounty.ca
The City of Kawartha Lakes	26 Francis St., Lindsay	705-324-9411	www.city.kawarthalakes.on.ca
The County of Haliburton	11 Newcastle St., Minden	705-286-1333	www.haliburtoncounty.ca
The City of Peterborough	500 George St., N., Peterborough	705-742-7777	www.peterborough.ca
The City of Toronto (Scarborough)	150 Borough Dr., 4 th floor, Toronto	416-392-2489	www1.toronto.ca

- 7. **Anishnawbe Health Toronto** offers healthcare based on traditional Aboriginal practices and approaches. This includes mental health supports and counselling. Call 416- 360-0486, Website: www.aht.ca
- 8. **Canadian Cancer Society** offers information about cancer. They can also connect you with a person to talk to about your feelings. Call 1-888-939-3333, Website: www.cancer.ca

- 9. **Cardinal Nannies** has a team of professional nannies offering child care for a fee. Call 1-800- 219-8059, Website: www.cardinalnannies.com
- 10. Central East Local Health Integration Network (LHIN): Home and Community Care Program. The LHIN offers healthcare at home, at school, or in the community. Care Coordinators will help you get the care and services you need. Call 1-800-263-3877, Website: www.healthcareathome.ca/centraleast/en
- 11. **Kids Help Phone** is a free phone and web service that offers information to kids. They also provide private counselling for any problem a child is worried about. Call 1-800-668-6868, Website: www.kidshelpphone.ca
- 12. **Niijkiwendidaa Anishnaabekwewag Services Circle** offers counselling and healing services if you are Anishnaabekwewag. Call 1-800-663-2696, Website: www.niijki.com
- 13. **Nanny Angel Network** has a team of volunteer professional childcare workers that offer child care to mothers with cancer. Call 416-730-0025, Website: www.nannyangelnetwork.com

Books

Many of the books on this list can be borrowed from the library at Hearth Place Cancer Support Centre or can be ordered at www.amazon.ca

For Preschool and School Aged Children

A Day with Dr. Waddle (Ages 4-10) By Centre for Basic Cancer Research A duck scientist tells about cancer. It has pictures to colour and puzzles to solve.

A Dragon in Your Heart (Ages 4-8) By Sohpie LeBlanc

Written by a mother with breast cancer for her 5-year old daughter. She provides details about cancer and how chemotherapy works.

Because . . . Someone I Love Has Cancer: Kids' Activity Book (Ages 4-12)

By American Cancer Society

This book will help support children who have a loved one with cancer. It comes with crayons and an activity book.

Becky and the Worry Cup (Ages 5-12)

By Wendy S. Harpham, M.D.

Is the story of a 6-year old girl whose mom has cancer. It also talks about how to deal with cancer coming back. There are many examples of how to help children cope, when a family member has cancer.

Butterfly Kisses and Wishes on Wings (Ages 3-7)

By Ellen McVicker

The story is told from a child's point of view. It gives simple details about cancer. It also teaches how a child can help a loved one who has cancer.

Kemo Shark

Is the hero of a comic book. He talks about changes when a parent has cancer and starts chemotherapy treatment. Available at www.issuu.com/marynelduran/docs/kemoshark/8

Let My Colors Out: A Pop Up Book (Ages 4 and up)

By Courtney Filigenzi

A young boy uses colour to share different emotions as his mother undergoes cancer treatment. Some days he is sad, some days he is happy, and other days he is scared or angry. The boy comes to learn that these ups and downs are perfectly normal.

Life Isn't Always a Day at the Beach (Ages 4 to 13)

By Ganz High Five Publishing

Is a cartoon workbook for children, where they can colour, write or draw. It helps children understand their feelings when their parent has cancer.

Mom and the Polka-dot BooBoo (Ages 4-8)

By Eileen Sutherland

This book helps families talk about breast cancer. It gently prepares children for what may come.

Mom Has Cancer (Ages 4-7)

By Jennifer Mallinos

Encourages children to talk about how they are feeling when mom has cancer.

My Daddy's Cancer or My Mommy's Cancer (Ages 2-8)

By Cindy Klein Cohen and John T. Heiney

These two stories are the same. Choose what story to read based on which parent has cancer. There is a colouring book and activities for children.

Nowhere Hair (Ages 4-8)

By Sue Glader

This book is written in rhyme. It explains hats, scarves, wigs, and going bald when in public. It talks about being nice to people who may look a little different. It ends with the idea that what is inside of us is more important than how we look on the outside.

Once Upon a Hopeful Night (Ages 4-10)

By Risa S. Yaffe, Troy Cramer (illustrator)

Explains cancer and treatments and the feelings that go along with them.

Our Dad Is Getting Better (Ages 4-12)

By Alex Silver, Anna Rose Silver, Emily Silver

Written for children whose parents are cancer survivors. It helps families move on after treatment ends. It has a message of hope and healing. It touches on the topics of: recurrence, ongoing side-effects, exercise and diet, rest and sleep, and returning to work and social life.

Our Family Has Cancer Too (Ages 8-12)

By Christine Clifford and Jack Lindstrom

It tells the story of a 6th grader and his younger brother, whose mom has cancer. The boys visit her in hospital and learn about radiation and chemotherapy. They also help with chores at home. This story has a glossary of common terms, "Questions to Ask" section, worksheets, and encourages discussion between parents and children.

Please Don't Go (Ages 9-12)

By Mary Jo Valley

A young girl's story about her mom having breast cancer.

Promises (Ages 3-8)

By Elizabeth Winthrop

A little girl deals with her mother's cancer. She faces anger, other children's reactions and her mom's hair loss. It talks about "making plans for today" and not making promises.

Sammy's Mommy Has Cancer (Ages 3-8)

By Sherry Kohlengerg

This book talks about the changes that occur in a family when a mother is diagnosed with cancer.

The Goodbye Cancer Garden (Ages 5-8)

By Jenna Matthies

Children decide to plant a garden after being told that mom has cancer.

The Hope Tree – Kids Talk about Breast Cancer (Ages 4-8)

By Wendy Schlessel Harpham, MD, David M. McPhail (illustrator) and Laura Joffe Numeroff Animal characters talk about their mom's breast cancer.

The Invisible String (Ages 4 and up)

By Patricia Karst

This is a great story to read if you are going to be in hospital for treatment and away from your child. It tells us that we aren't ever really alone. And that we can love beyond anything we can imagine.

The Paper Chain (Ages 3-8)

By Claire Blake, Eliza Blanchard, Kathy Parkinson

A story of two young children whose mother has cancer. It talks about missing mom when she is in hospital. It gives creative ways of coping. It also talks about feelings of anger. This story gives a good example of how to talk with children about cancer.

The Rainbow Feelings About Cancer (Age 4 and up)

By Carrie Martin and Chia Martin

This book encourages conversations about cancer between children and those who love them. Children are encouraged to share their feelings and ask questions.

Tickles Tabitha's Cancer-tankerous Mommy (Ages 4-8)

By Amelia Frahm, Elizabeth Schultz (illustrator)

A little girl and her family learn to cope when a parent is diagnosed with cancer.

Upside-Down Cake (Ages 9-12)

By Carrol Carrick

A 9-year old boy deals with his father's terminal illness and death in this chapter book.

When Someone Has a Very Serious Illness (Ages 5-12)

By Marge Heegaard

A cartoon workbook for children to colour themselves. It helps them understand their feelings when their parent has cancer.

When Someone You Love Has Cancer: A Guide to Help Kids Cope (Ages 4-12)

By: Alaric Lewis

This book helps children cope when a family member has cancer.

You Are the Best Medicine (Ages 3 and up)

By Julie Aigner Clark and Jana Christy

Cancer survivor Julie reminds us how children can care for a family member at a time when love is most needed.

For Teenagers

Both Sides Now (Ages 13-18)

By Ruth Pennebaker

Is about a teenaged girl and how her life changes when her mother's breast cancer returns.

Mama's Going to Buy You a Mockingbird (Ages 12-16)

By Jean Little

A teenage boy struggles with dealing with his father's terminal cancer.

My Mother's Breast: Daughters Face Their Mother's Cancer (Ages 16 and Up)

By Laurie Tarkan

Stories from women of a variety of ages (as young as 17) dealing with their mother's cancer. Mature content - not recommended for younger teens.

My Parent Has Cancer and It Really Sucks: Real Life Advice from Real Life Teens (Ages 12 -16)

By Marc Silver and Maya Silver

This book helps guide teens through the experience of having a parent with cancer. It offers "survival

tips" from other teens who have experienced cancer firsthand.

Saying it Out Loud (Ages 12-18, young adult)

By Joan Abelove

A 16-year old girl struggles with her mother's terminal brain tumour.

When Your Parent Has Cancer: A Guide for Teens (Ages 12-16)

By National Cancer Institute and National Institutes of Health

This book includes information about cancer treatments, ways teens can talk to family and friends, how to connect with other teens, and where to find other resources for information and support.

Available at www.cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf

For Parents

Can I Still Kiss You? Answering Your Children's Questions About Cancer

By Neil Russell

This book will help parents speak to their children about cancer.

Cancer In Our Family: Helping Children Cope with a Parent's Illness

By Joan F. Hermann, Sue P. Heiney

This book includes steps to take to help children understand what happens when a parent has been diagnosed with cancer, how to talk to children about it, and how to answer difficult questions about cancer.

How to Help Children Through a Parent's Serious Illness

By Kathleen Mccue

A good overview of issues related to serious illness.

Raising an Emotionally Healthy Child When a Parent is Sick

By Paula Rauch

This book helps parents understand their child's development, emotions and reactions at a difficult time. It supports parents as they encourage and help their child cope.

When A Parent Has Cancer: A Guide to Caring For Your Children

By Wendy Harpham

In this book, a physician, mother and cancer survivor offers stories and examples for talking to children about cancer

When a Parent is Sick – Helping Parents explain Serious Illness to Children

By Joan Hamilton

This book has examples of how to talk with your child. The author outlines differences in ages and how they understand, process and adjust.

Websites

These websites are included for your information on children's coping. The American websites may have information that is not part of Canadian medical practice. Children can also look at these websites if you think the content is appropriate.

American Cancer Society

The on-line version of the brochure **Helping Children When a Family Member Has Cancer: Dealing with a Parent's Terminal Illness**

www.cancer.org

Canadian Cancer Society

"Helping Children Cope" section includes ages and stages of understanding and helping your child to cope with your diagnosis.

www.cancer.ca

Telling Kids About Cancer

This helpful website talks about how to begin to talk about your diagnosis with your children. It includes video testimonials, resources and planning sheets.

www.tellingkidsaboutcancer.com

The National Cancer Institute

Includes age appropriate booklets on talking to your children about your cancer. www.cancer.gov/search/results

Videos

YouTube

"Someone in my family has cancer: A video for kids and parents" www.youtube.com/watch?v=u1erqxA_0uk

Produced by Lundbeck Canada

Camps

Camp Keaton: is an annual three-day camp offered at no charge. It is run by staff and volunteers of the Dr. Bob Kemp Hospice and Bereaved Families of Ontario - Hamilton/ Burlington. The camp is for children ages 6 to 17 who have experienced the death of someone close to them. Call 905-387-2448, Website: https://kemphospice.org/camp-keaton

Camp Erin Toronto: is a weekend-long camp offered at no charge. It is run by staff and volunteers of the Dr. Jay Children's Grief Program, The Temmy Latner Centre for Palliative Care. The camp is for children aged 6-17 who've experienced the death of a family member. Some years they hold camp in June and others in September, and there is no cost. Call 416-586-4800 Extension: 6664, Website: www.drjaychildrensgriefcentre.ca/programs/camp-erin/l

Cottage Dreams: offers cancer survivors the opportunity to spend a week at a donated cottage. This much needed time away with survivors, their friends and families allows them to reflect and celebrate recovery. Cottage Dreams is available to all Canadian residents of all ages and types of cancer who will have completed their treatment within two years prior to their Cottage Dreams getaway. Call 705- 457-9100, Website: www.cottagedreams.ca

Gilda's Club Toronto: Runs camps in week-long blocks throughout the summer. Different age groups are run for different weeks during the summer, as well as during the winter and March Break. The camps are called "Camp in the City". The campers have someone in their life that has or had cancer – this may be a sibling, parent, grandparent, etc., and they may be currently ill, in remission or they may have died. There's no cost for the camps. Call 416-214-9898, Website: www.gildasclubtoronto.org/camp-in-the-city/

The Coping Centre: Runs summer camps for grieving children, called Adventure Camp. It provides a unique way to support grieving children. Call 1-877-554-4498, Website: www.copingcentre.com

Young Carers: A group supporting children, teenagers and young adults who are involved in helping to care for their family or a particular family member when someone is ill. They have free programs and camps as well. Call 416-364-1666 extension 245, Website: www.ycptoronto.com

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