

Talking to Children About Cancer

A GUIDE FOR FAMILIES
AND CARE PROVIDERS



HOPE & COPE
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WHAT IS CANCER?

Simply put, cancer is a disease of the cells, which multiply and grow into tumors. It can affect different internal organs, systems and body parts.

When a family member is diagnosed with cancer, it can cause fear and uncertainty for everyone, especially children. More parents are being diagnosed with cancer than ever before. It is helpful to understand how children react to the news and how they cope with their parent's illness.

This booklet gives parents general tips on talking to their children about cancer using words that they will understand. It's important to keep the lines of communication open, to encourage honest conversation and to provide reassurance whenever possible. Remember that you know your children best.

THE FIVE W'S OF TALKING TO CHILDREN: WHEN, WHERE, WHY, WHO AND WHAT

When

Set up a quiet time when you won't be disturbed. Weekends might be best since weekdays are usually busy with school activities, homework, appointments, or extracurricular activities. It should be a time when the ill parent is well-rested and energized.

Why

Overprotecting your child or hiding the truth may do more harm than good. Children may imagine the worst if they are not told otherwise. Sooner or later, the children are going to find out and you would not want them to find out from another source.

EXPLAINING THE DIAGNOSIS

"I have an illness called cancer. The doctor is giving me some medicine to help me get well. The medicine might also make me feel sick or tired some days but other days I will be fine."

"The doctors say that Dad has a problem with his blood. That is why he is very tired lately. The illness is called (type of cancer). He will have treatment to make him better."

Where

Find a quiet place with no interruptions where the family can discuss this together.

Who

Decide in advance who are the best people to tell the children. If possible, it should be the parent who has the cancer along with the other parent. If this is not possible, any close relative or adult in the child's life or a caring medical professional could also explain. You may wish to talk to each child separately so that information can be tailored to each child's age and level of understanding.

What

Over the period of the illness, there will be a lot of information passed along to the children. At the beginning, all children need to know the following basic information: the name or type of the cancer, the part of the body where the cancer is, how it will be treated, and how their own lives will be affected. Explain this to them using basic words and language that they can understand.

12 HELPFUL TIPS FOR CHILDREN OF ALL AGES

1. Be truthful about your diagnosis with age-appropriate information. Let them know that they can come to you at any time with questions and concerns.
2. Start simply and give out information in small doses rather than overloading them with everything at once.
3. Keep in mind the age difference between each child in the family. They may need to be told different information at different times. A “family meeting” may not always be appropriate.
4. Take advantage of any and all resources available in your community.
5. Share your family health situation with any significant adult in your child’s life such as teacher, coach or mentor. This will help them to understand and to report to you any changes in behavior that might occur. These adults may also help maintain your children’s routines, as well as listen to their feelings and concerns.
6. Enlist family members or friends to help, thus reassuring the child that their daily lives will remain as normal as possible and that they will be well looked after.
7. Keep them in the loop. Explain as much as possible about treatments, side effects or hospitalizations in advance so that they will understand what to expect.
8. Being honest while having these difficult discussions is an opportunity for children to learn about uncertainty and how to cope when life does not go as planned.
9. Be a good listener. Listen to all of their worries or concerns, no matter how trivial you think they may be. Encourage dialogue and questions.
10. Balance hope with reality but do not make promises that you cannot keep.
11. Be mindful that it is normal for children to have many emotions. It is okay to laugh, cry or even be silent. Anger, fear, anxiety and depression are all normal emotions experienced by children of any age.
12. Although it may be difficult, it is important to set boundaries (e.g., discipline, routines, responsibilities).



DEVELOPMENTAL STAGES OF CHILDREN

Age is an important factor in deciding what and how much you should tell a child about a cancer diagnosis. The goal should be to tell the truth in a way that children are able to understand and thereby prepare themselves for the changes that will happen in the family.

A CREATIVE EXPLANATION

"I have an illness called cancer. It means something is growing inside my body that shouldn't be there. I am going to have an operation to have the cancer taken out and some more treatment to make sure it doesn't grow back."

PRESCHOOLERS (3-5 YEARS OLD)

Children of this age have a basic understanding of illness. They think simply and concretely. They understand today, yesterday and possibly that something happens later: not an abstract concept such as the "future." They view "hurt" or "sick" as short-term events. "Very sick" or "really sick" may not mean more to them than just "sick."

They believe that their thoughts and actions affect the world around them ("magical thinking"). Therefore, when told about a parent's cancer, they may think such things as: Did I cause it? Can I catch it? Who will take care of me? Getting better will just happen by itself or will come by doing what the doctor says.

Reactions/How Children Cope

A toddler's reaction to a parent's illness is generally centered on themselves and how it affects them and the changes in their routines. They may:

- Revert to earlier behaviours because they are not getting the usual attention from the sick (or healthy) parent (e.g., bedwetting or waking up in the night).
- Be angry at all family members for the changes and disruption the sickness is causing.
- Attach themselves very closely to a "substitute" parent.
- Become more active, aggressive or extra quiet. This does not mean they are unaffected.
- Listen to your explanations of what is happening and then quickly return to play.
- Act by imitating others (e.g., if others are crying they will cry).
- Seek comfort by using a security blanket or favourite toy.
- Develop fears (e.g., darkness, strangers, monsters, nightmares).

ADDRESSING THEIR FEARS

Does it hurt?

"Cancer doesn't always hurt, but if I have pain, the doctors will give me medicine to help make it go away."

How a Parent Can Help

- Try to be patient and give your children extra love and attention whenever you can. Hug your child and maintain physical closeness. If this is not always possible, try to find someone they trust to spend extra time with them.
- Try to keep your child in familiar surroundings. If a parent is hospitalized, keep some of your child's games, toys and books at the hospital for his/her visits.
- Encourage expression of emotions through music, art or physical activities.
- Explain and reinforce that they did not do anything to make their parent sick and neither did the parent. Be matter-of-fact and brief with information.
- Share your feelings (e.g., "I hurt inside," or "I am sad too"). Reassure them that they and the well parent are not sick. Use a calming voice when explaining what is happening.
- Use picture books, dolls or stuffed animals to help with explanations or answers to questions.
- Reinforce that they cannot catch cancer and it is ok to hug and kiss.
- Encourage them to keep having fun and to be physically active every day.
- Continue with regular discipline and limit-setting.
- Watch TV or movies together and talk about their school day.

CREATING A SENSE OF SECURITY

Who will look after me?

"We will try to keep things as normal as possible, but there may be times when I have to ask dad/mum/grandpa to help out."

BEING HONEST

Are you going to die?

"I don't know what will happen in the future, so let's think about what's going on right now. I promise that I will tell you when I find out new information".



YOUNG SCHOOL-AGE CHILDREN (5-8 YEARS OLD)

Children of this age group have an understanding about the past and present but are still unclear about the long-term future. They may have heard about cancer but have a very basic understanding. They may ask questions such as “How did mommy get cancer?” or, “Will I get it?” They know that treatment and medicine can help you get well, but usually don’t fully understand that illness can be life threatening. They continue to play, but have started to think logically and will express feelings about what is happening. It is important to remember that children will quickly return to the security of playing or pretending when they have heard enough.

BEING HONEST

Are you going to die?

“The doctors have told me that my chances of getting better are very good. I believe them and I want you to believe them too. They are doing everything to help me get better.”

Reactions/How Children Cope

Children of this age react both physically and emotionally when they hear that a beloved parent has cancer. They may:

- Be angry if the sick parent promised to go do something with them and now cannot, or if their usual activities are disrupted.
- Focus on hospital equipment and technical things.
- Want to continue with normal outside activities, as if the parent is not sick.
- Have difficulty adapting to changes.
- Become angry or hostile towards parents, friends or other family members.
- Have trouble concentrating or are easily distracted.
- Complain of physical ailments such as stomach or headaches.



How a Parent Can Help

- Be prepared to explain the illness, treatment and equipment honestly and in age- appropriate language. Books and stories can be helpful.
- Try to be patient when children seem selfish about how the illness is affecting them.
- Show your feelings openly and encourage your children to share theirs with you.
- You can keep hospital visits and discussions brief unless your child desires otherwise. It is good to keep games, toys and books at the hospital so your child has something to do during a visit.
- Give your child many opportunities to talk, but be prepared to also just “be together.”
- It is important to reassure your child that he/she will continue to be cared for.
- Explain that it is normal to feel angry or sad.
- Always reinforce that the parent is not sick because of something they did or did not do.
- Reinforce that they cannot catch cancer and that they and other members of their family are healthy.
- If a parent is hospitalized, encourage the child to draw pictures or send a card.
- Watch TV or movies together and talk about their school day. Encourage physical and creative activities.
- Giving children simple tasks, such as bringing water or an extra blanket, helps them feel connected and involved.

BEING TOGETHER

Why do you need to rest so much?

“The operation/treatment I’m having has made me tired and I need to rest a lot so my body can recover and get better. Why don’t we make a plan for where we’ll go or what we’ll do on a day I have more energy? Perhaps today we can do something quiet together like watch a movie.”



OLDER SCHOOL-AGE CHILDREN (8-12 YEARS OLD)

At this stage, children are beginning to think abstractly but still continue to think logically. They will ask “how” questions, searching for understanding, answers, and how things work. They now understand the concept of a “future.” Your child is familiar with what cancer is but does not necessarily understand the reason for the symptoms or the disease process itself. From the ages of 8 to 12, children are starting to move outside family to develop relationships and are shifting their focus from family to friends. The illness now is often centered on how it affects them socially. Rituals and traditions are still important to them.

Reactions/How Children Cope

Emotionally, the child is struggling to be grown-up and wants to show this by being independent. They may:

- Try to cover up feelings and behaviours like crying to avoid being seen as childish.
- Choose to share or not share their feelings with others. They will commonly show anger before sadness, and may act out against other family members.
- Be afraid that they themselves are not healthy.
- Blame themselves for the illness.
- Focus on how their parent’s illness has disrupted their life and may not show concern for the parent.
- Ask for specific information about prognosis and treatment.
- Feel guilty for feeling angry, for being healthy, and for wanting to have fun when their parent is sick.

How a Parent Can Help

- Be patient when your child seems self-centred about how the illness is affecting them. They do not know how to look at things any other way.
- Sometimes, a child’s “bad” behaviour may be the way that upsetting feelings come out. Instead of punishing, try to be patient and talk to them. Validate their fears and discuss their concerns.
- You can give your child some added tasks, but don’t overload him/her. Focus on chores that apply to them, such as making their lunch or their bed.
- Allow them to participate, if they wish, in the care of the sick parent with tasks that are appropriate such as straightening the blankets or bringing food.
- Children may perceive physical contact as “not cool,” so you will usually need to be the one to initiate hugging and cuddling. They may not want you to be overly affectionate, especially in front of their friends.
- Children are very focused on their social lives, so it is important to prepare for difficult encounters. Talk about how the child can react to peers’ comments and questions. You can offer to help talk to your child’s friends and/or their parents.
- Encourage your child to continue involvement with friends and outside activities. Try to keep as normal a schedule as possible.
- Watch TV or movies together and talk about their school day.



ADOLESCENTS (13-17 YEARS OLD)

Talking to your teenager about a cancer diagnosis, treatment, and prognosis might be one of your biggest challenges. At this stage in your child's life, they are trying to be more independent and may be withdrawing from family. Although they are focused on relationships with friends, they are still dependent on family in many ways. They are struggling to be the same as their friends and wanting to fit in. Peer pressure may cause moodiness and experimenting. They will start to disagree frequently with you over rules and values, and want to become self-reliant. At this age, children are familiar with cancer and understand that there are different types and varying outcomes, possibly death. Your child now understands the significance of a serious illness. They have a general understanding of how the body works and therefore will most likely understand your symptoms and the reason behind them.

ADDRESSING CHILDREN'S CONCERNS

Why do you look so sick when the doctors are supposed to be fixing you?

"The doctors are using strong medicine to kill the cancer, but the medicine affects good cells as well as cancer cells. Some days I will feel and look sick, but this doesn't mean the cancer is getting worse. I will start to feel better when treatment finishes."

Reactions/How Children Cope

Behaviours vary from child to child, but they will all struggle to balance being with friends and living their own lives, with staying close to sick parents. They tend to cope better than young children because their parents are not the only people in their lives now, and friends can be supportive and encouraging. At this age, they may:

- Worry about the sick parent's future.
- Be concerned with the discomfort, pain, and suffering of their sick parent.
- Be afraid to show feelings for fear of completely breaking down.
- Direct their anger toward any family member, or the sick parent.
- Take on more responsibility for younger siblings.
- Take charge of more household duties.
- Try to do everything to help, even giving up their activities or social lives to be helpful at home.
- Pull away and distance themselves, or become sullen and withdrawn.
- Act self-centered.
- Study harder at school to get good grades in order to please parents.

How a Parent Can Help

- Acknowledge how hard it must be to feel torn between spending time with the parent and spending time with friends. Encourage them to carry on with some of their normal activities with friends.
- Involve your children in some decision-making and activities, but do not pile too much responsibility on them or make them assume adult roles.
- Define the limits and what you expect from your child, as well as what the adult's responsibilities will be.
- Encourage your teen to talk to you and answer their questions openly and honestly.
- Let them know about people and places they can go to for more information and support.
- Respect your teen's privacy. They may want to talk only to certain people about their loved one's illness. Make sure there are other people they can go to for support - perhaps a close relative or a family friend - but let your teen decide if they want to or not.
- Let them know it's okay to have fun in spite of coping with cancer.
- Inform them of any upcoming changes in their routines.
- Watch TV or movies together and talk about their school day and friends.



EXPLAINING RADIOTHERAPY AND CHEMOTHERAPY TO CHILDREN

Explaining the different cancer treatments you may experience can be very tricky and unsettling to children. Explaining it to them in an appropriate manner can make all the difference in helping them to accept the changes. Try to answer questions using words that are easy to understand and do not give more information than necessary.

General Guidelines

1. Give the child advanced notice. Talk to your child before the treatment starts about what it will be like and how you may change. This will give them time to digest the information.
2. Take your child's age into account. Explaining chemotherapy to a preschooler is very different than explaining it to a teenager. It is important to validate what they already know about cancer and adjust your explanations when necessary.
3. Focus on how treatment will affect them. Reassure them that their regular routines and activities will carry on in as normal a way as possible with the help of other adults.
4. Don't be afraid to explain the side effects you may have and that the treatments will help you get rid of the cancer and make the parent better.
5. Encourage your children to ask any questions they may have.
6. You may need to ask your health-care professional to assist in this delicate conversation.

RADIOTHERAPY

Radiotherapy is a type of cancer treatment that uses radioactive rays to kill cancer cells. Treatments are painless and usually take only a few minutes. There are some side effects which can last a little while after the treatment is over such as fatigue or redness of the skin on the treated area. Children are smart and want to understand what is happening so explain the treatment to them in a manner they can understand. It is important to be clear and to try and simplify what is going on.

ANSWERING QUESTIONS ABOUT TREATMENT

Does Radiotherapy make you radioactive?

"Radiotherapy is like an x-ray. It doesn't hurt. It's safe to touch me."

Child-Friendly Explanations

- "You know the special camera that takes pictures of the inside of your body? It's called an X-ray machine. There's a special kind of X-ray machine that helps the cancer go away. Lines are usually drawn on the body where the radiation will be aimed at. These lines aren't permanent and can be washed off."
- "Your dad is going to have a treatment that might make him very tired. When he gets home, he will need lots of rest."
- "Grandpa may not be able to play with you as often as he wants, but he loves you very much."

CHEMOTHERAPY

Child-Friendly Explanations

- “Chemotherapy is a kind of cancer treatment that uses special kinds of medicine to destroy fast-growing cancer cells. These medications enter the bloodstream to be carried to cancer cells anywhere in the body.”
- “Daddy is getting some medicine to help him get better. The medicine is called chemotherapy. It kills cancer little by little.”
- “Chemotherapy is usually given many times for several months or years.”

EXPLAINING SIDE EFFECTS

Will your hair grow back?

“The doctor says I may lose my hair because of the chemotherapy. It will come back but probably will look a bit different, especially at first. I can wear wigs, scarves or hats until it grows back.”

Different ways to receive chemotherapy

1. Through a needle inserted in a vein (IV)
2. Through a needle into a muscle
3. Liquid and pill forms taken by mouth

Side Effects Of Chemotherapy

While chemotherapy has a positive effect in killing cancer cells, it usually has several side effects. On the bright side, many of these side effects don't last long and will gradually go away after treatment is stopped. Remember that once the chemotherapy is over, people usually begin to feel a lot better. Reinforce that everyone reacts differently to chemotherapy. Some of the side effects might include:

1. Loss of hair (however, it usually grows back after treatment is over)
2. Nausea and vomiting
3. Sore mouth
4. Fatigue
5. Loss of appetite which can lead to weight loss



10 TIPS FOR SINGLE PARENTS FACING CANCER

Being a single parent with young children can be difficult; being on your own with young children and having a cancer diagnosis brings a whole range of different challenges.

Although the information in this booklet is of a general nature, here are some points that may be helpful if you are a single parent:

1. When first telling your child about your diagnosis, it may be a good idea to ask a close relative or friend to be there. If that is not possible, you may want to choose any health-care professional who knows your history, such as a social worker or nurse.
2. For single parents, the key issue is choosing the best caregiver for your child or children. For some, family members may not be an option, but it's less scary for the kids if it's someone they know or can get to know before beginning treatments or are hospitalized.
3. This may be easier said than done, but remember that it is very important to take care of yourself. If you're feeling unwell or simply exhausted, it's often hard to carry on doing the things you normally would. Keep in mind that self-care, a little exercise, rest, and a good diet are all ways you can be good to yourself.
4. Set small boundaries and goals for yourself as a parent.
5. As a single parent, you have struggled to achieve independence. However, it may be necessary to ask for help from time to time. Take advantage of any other parents who might be willing to help. Do not isolate yourself or turn down help.
6. Getting the right support is essential. Find out what services and programs are available in your community.
7. You may be able to get some financial support. Work with your hospital social worker to see if you are eligible to receive grants or take advantage of government or private-funding assistance.
8. Use the buddy system. You may be able to hook up with another single parent in a similar situation both to talk to and to share resources, responsibilities and even childcare.
9. Get active in the cancer community. Become involved in local cancer walks and activities to support others.
10. You may need the help of your older children, but be mindful of giving them too much responsibility.



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LIFE AFTER TREATMENT: A “NEW NORMAL”

For many people, the end of treatment can be a time of mixed emotions for both patients and their families. Children and teenagers may expect life to return to normal straightaway, but for the person who has had treatment this may not be the case. You and your family might need to find a “new normal” and this can be an ongoing process. The physical effects of cancer can last long after the treatment is over and many changes will now be incorporated into your life, including fatigue, dealing with physical scars, lymphedema, early menopause, nutrition, or fertility and sexuality problems.

Children of any age may find it hard to understand why things simply can't go back to the way they were before the cancer. They've had to make adjustments while their parent or other loved one was sick, and now they want to get back to normal. They may have difficulty seeing that this is not the case and that life cannot return to exactly the way it was before. And of course there is always the fear that the cancer might return.

What can you do?

- You may need to reassure your children that regular check-ups will help monitor the cancer.
- Thank your kids for their help, support and contribution to your recovery.
- Acknowledge the sacrifices your family has had to make: this is particularly important for teenagers.
- Encourage kids to have fun.
- Keep communicating and sharing your feelings.
- Do things at your own pace, and avoid pressure to return to 'normal' activities.
- Do things together such as light exercise, playing or cooking.
- Remember to keep looking after your own wellbeing, taking one day at a time. This will be of benefit to both yourself and your children.



SOME CHILD-FRIENDLY GLOSSARY OF TERMS

Biopsy (by-op-see)	A procedure that removes a piece of tissue from a person's body and examines it under a microscope. This is done to see if a patient has cancer and if so, what kind.
Cancer	The name for a disease in which cells that are not normal grow and divide quickly. These cells usually develop into a tumor (a lump).
Diagnosis (dy-ag-nosis)	Finding out the exact disease that is causing a person's illness.
Lymph nodes (limp-fff nodes)	Small bean-shaped bumps that are like filters that remove germs from your body.
Malignant (muh-lig-nunt)	Malignancy is another word for cancer.
Mastectomy (mass-tect-o-me)	Surgery to remove a breast, or part of a breast.
Metastasize (met-tass-ta-size)	The breaking away of cancer cells from the original tumor, settling somewhere else in the body, causing a new tumor.
Oncologist (on-call-o-jist)	A doctor who specializes in treating cancer.
Recurrence (re-ker-ince)	When cancer comes back and the person feels sick again.
Remission (re-mish-in)	When cancer goes away after treatment. A complete remission means no sign of cancer is found on tests, scans, and physical exam.
Scan	A picture of a particular part of the body.
Side effects	Problems caused by cancer treatments or other medicines (fatigue, weight loss).
Surgery or Operation	A procedure that usually involves cutting open part of the body. It is done by a doctor who is an expert in doing operations.
Tumor	An abnormal bunch of cells grouped together into a lump. Some tumors are cancerous and some are not.

SOME OF THE INFORMATION IN THIS BOOKLET HAS BEEN ADAPTED FROM THE FOLLOWING SOURCES:

- American Cancer Society
- Canadian Cancer Society
- Cancer Council New South Wales
- National Cancer Institute: When a parent has Cancer: A guide for Teens
- U.S Department of Health and Human Services
- What About My Kids: A Guide for Parents Living with Breast Cancer, Linda Cosini, Canadian Breast Cancer Foundation, Ontario, 2007.
- When a Parent Has Cancer, Wendy Harpham, HarperCollins Publishers, New York, 2004.
- When a Parent is Sick, Joan Hamilton, Pottersfield Press, Nova Scotia, 1999.

RESOURCES

A comprehensive list of resources can be found on the Hope & Cope website:

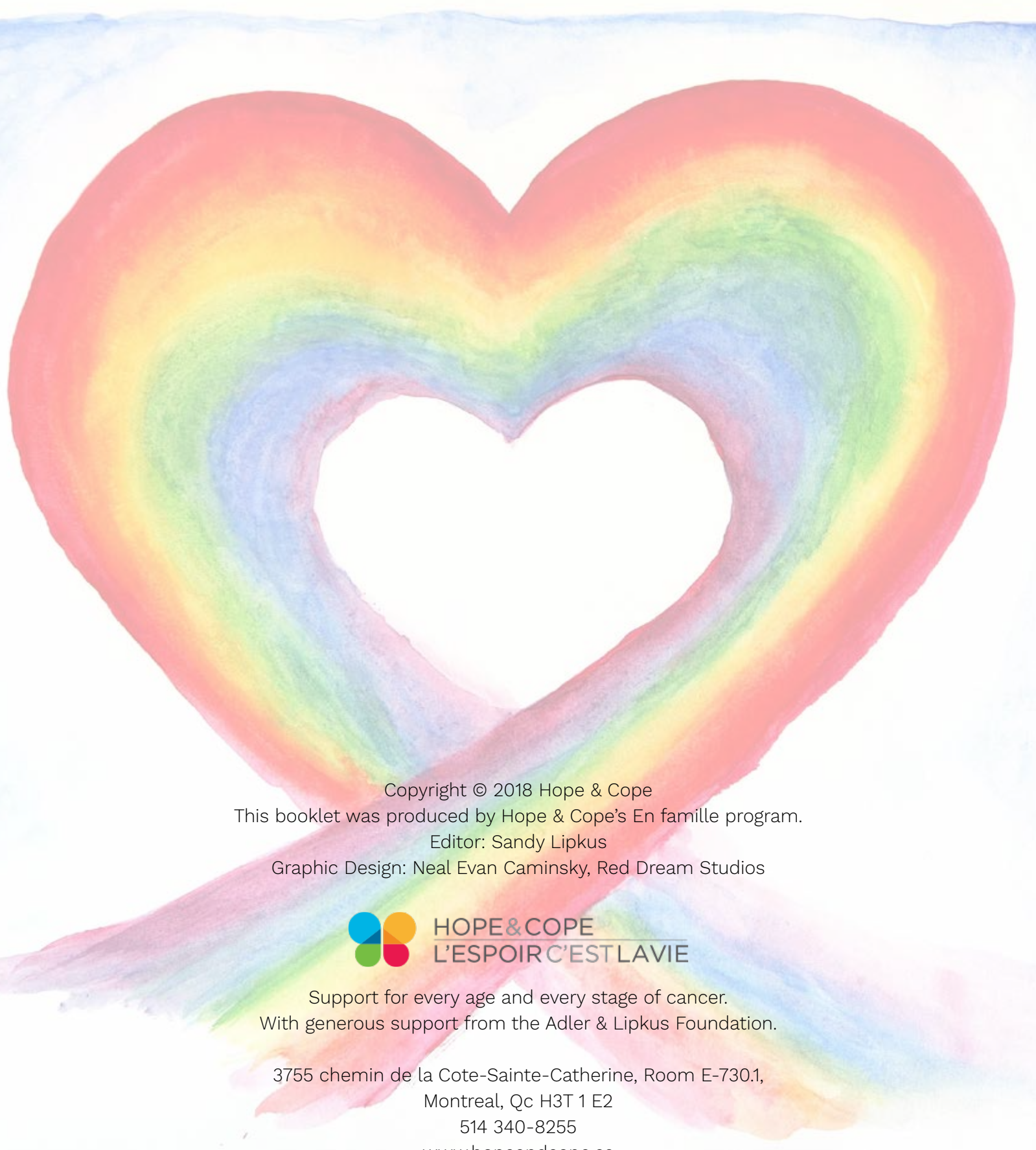
<http://www.hopeandcope.ca>

Below are a few short videos that you may find helpful:

<http://bit.ly/2IA0M2k>

<https://youtu.be/-bAV5hWwF8Y>

<https://youtu.be/SrdQBZJ9bXk>



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With generous support from the Adler & Lipkus Foundation.

3755 chemin de la Cote-Sainte-Catherine, Room E-730.1,
Montreal, Qc H3T 1 E2
514 340-8255
www.hopeandcope.ca

