



Parenting with Cancer

Explaining The Diagnosis

Bonnie Hobbs MSW, RSW

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Hope Courage Strength **FAMILY**

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Foreword

This guide has been developed by Bonnie Hobbs BSW, RSW as part of her Social Work Master's Program at Memorial University of Newfoundland. Bonnie is a Registered Social Worker whose area of interest is Oncology and Hematology.

The information, illustrations and suggestions in this guide are the result of Bonnie's passion and commitment to Oncological Social Work. She has completed the guide in collaboration with other health care professionals and from her many years of dedicated research. Her goal is to help cancer parents relay medical information to children of all ages in a meaningful and timely fashion.

I am a Health Care Professional of forty years with twenty years in Oncology and I also have a personal experience with cancer. In 1996, I was diagnosed with cancer and required 6 weeks of total body radiation therapy. I was married with three children – one pre-teen and two teenagers. I struggled to explain to them what was happening to my body and to allay their fears and to answer their many questions and concerns.

This guide would have made my task easier had it been available. I can assure the reader that this booklet will be beneficial to all cancer parents and their children!

We thank Bonnie for seeing the need for such an instructive booklet and bringing it to fruition. As a result of her efforts children of cancer parents everywhere can now be better informed and prepared for their cancer journey.

Dr. Adrian Lear
General Practitioner in
Radiation Oncology
Dr. H. Bliss Murphy Cancer Centre

Acknowledgements ●●●●●

I would like to acknowledge all of the patients and families I have worked with throughout my social work career specifically, the patients and families of 4 North A and the Ambulatory Treatment Clinic at the Health Sciences Centre in St. John's Newfoundland. I feel truly blessed to be involved with and to offer support during such a difficult and challenging time. I am honored to do the work I do, and hope that the following information can make a difference in ones cancer journey.

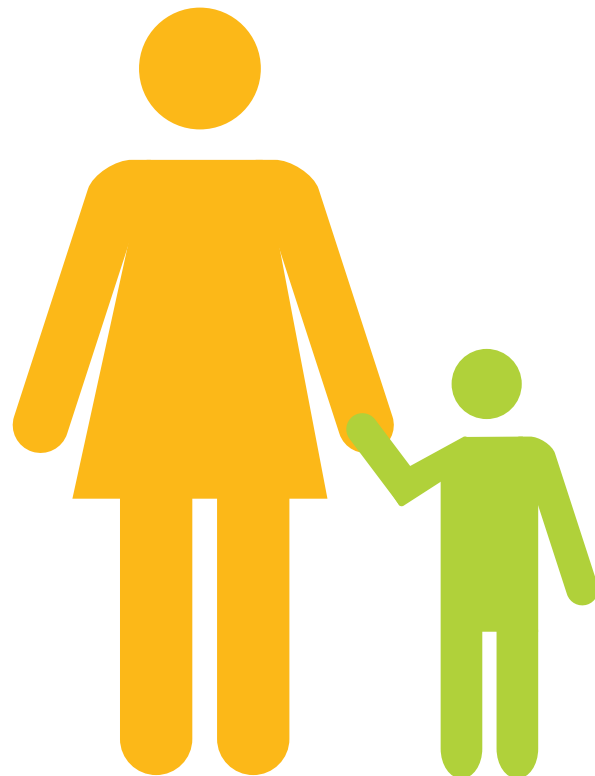
I would also like to acknowledge Memorial University School of social work, especially Dr. Mike Devine, RSW, Associate Professor at the School of Social Work Memorial University of Newfoundland who has been a true role model throughout my enrollment in the master's program. His guidance and consultation has made this guide possible.

I would like to thank Charlene Walsh Downey, Nurse Practitioner with the Hematology team for contributing to the glossary.

Bill Haynes, MSW, RSW, Paula Newhook, MSW, RSW, Carolyn Jones, MSW, RSW, and Elaine Holden, MSW, RSW, from the Dr. H. Bliss Murphy Cancer Centre for their input and edits.

Special thank you to Steffanie Martin from Nudge Designs for her amazing talent in the design of this guide.

Special thank you to Dr. Adrian Lear for the beautifully written forward and encouragement along my masters journey.



Notes



Introduction

This guide has been designed for adults who have been diagnosed with cancer and have children. Talking to a child about a cancer diagnosis in the family is a daunting task for most parents. As a social worker, I have worked with many families who have identified concerns and asked numerous questions about talking to their children following a cancer diagnosis.

**Including your child
in this discussion is
so important!**

There are many considerations when discussing a parent's cancer diagnosis with a child. This book will guide you through preparing for the conversation and will provide additional information about supporting your child. The goal is to educate you on your child's understanding of such illness and to provide examples of approaches and ways to initiate the conversation.

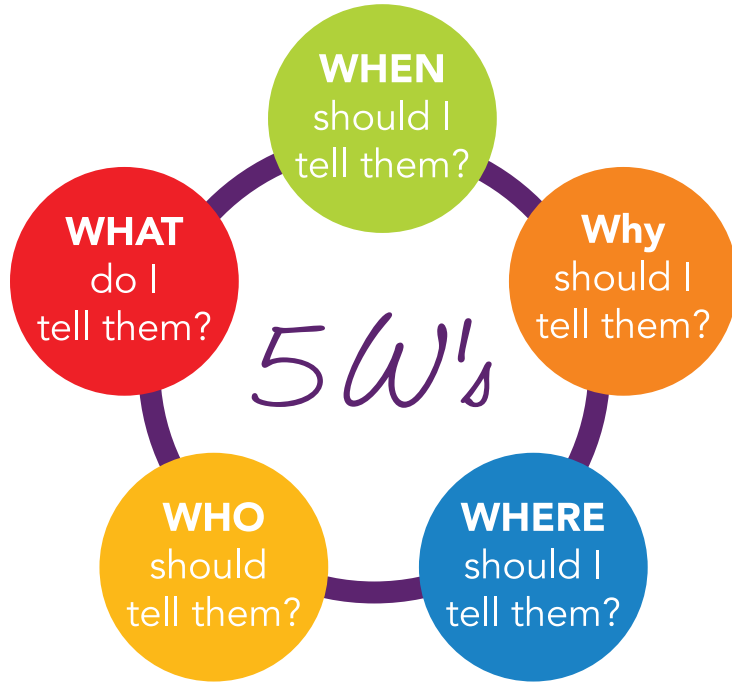
There are columns provided on each page to use as a notes section to allow you to document thoughts, questions, ideas or comments for your reference. There is also a notes section at the end of this guide to record or journal how you might talk to your child. Some things may prompt specific questions for you to ask your health care provider. It can also be used as a "to do list" as you read.

THE 5 W's of talking to your child about your cancer diagnosis

Talking to your child is an important step following your cancer diagnosis. It may also be one of the most difficult conversations you will have to have with your child. I hope that this information and guidance from your health care team will provide you with helpful information and will answer some of the lingering questions.



Five questions frequently asked by parents



Notes ● ● ● ● ●

🔍 *The WHY question: Why should I tell them?*

As parents it is a natural instinct to want to protect your child from daily family stressors. Understandably, you as a parent may have concerns that delay or stop you from explaining what is happening. The thought of coping with a child's distress on top of a cancer diagnosis may seem so overwhelming that it feels easier to avoid the issue.

Many parents sometimes feel that by not telling a child about a cancer diagnosis, they're protecting them. It might protect them initially, however long term it could create serious implications which could impact them even more. At a very young age, children can sense when something is

Use the notes section of this guide to help you with your thoughts on the approach that might work best for you and your family. Remember there is no right or wrong way to talk to your child. Also, your social worker is a good resource to help you prepare.

Remember: The following information should be used as a guide.

- Consider your child's age.
- When speaking with your child, use words that are common and familiar to them. **Refer to the glossary on page 13 in this guide to help you.**
- Keep in mind that children at different ages have different ways of understanding things. **Refer to the developmental stages on page 14.**
- Reflect on your child's past experience with cancer. If they know someone who has or had cancer or even if someone has passed away from cancer will impact on how you might prepare.
- If you have young children, they most often think of being sick in terms of catching germs. Let them know they cannot catch cancer like a cold. Reassure them you can hug and kiss each other just like always.
- Let children know about any changes to their routines and how this might impact their day.
- When talking about treatment, many children want to know what it will mean for them. For example, if Mom is in the hospital, who will take them to school, make dinner, or take them to after-school activities? Let your child know these concerns are important to you too. Reassure your child that there will be a plan and that you will let them know about it.
- Prepare your child for possible treatment side effects. Chemotherapy and other medicines that destroy cancer cells that can cause hair loss and weight loss, for example. This can be upsetting for your child. There are great books which discuss the physical changes of cancer. Refer to the books for children section in this guide.
- Keep in mind that your child's age will impact how much they understand.

You know your child best
so remember this as you prepare

Notes





Medical terminology can be
overwhelming
& **scary** for young children.

So the best advise is to keep it as
simple as possible.



Glossary

You may be asking yourself; “how do I explain this complicated disease to my child when I myself may have difficulty understanding or explaining the medical terminology?” The following terms were developed in consultation with Nurse Practitioner Charlene Downey, RN, MN, CON(c) to assist you in explaining to your child.

Biopsy: A procedure performed by a doctor to remove a piece of tissue from a person’s body. This allows the doctor to look at the tissue under a microscope to determine if the person has cancer, and what type of cancer it is.

Cancer: Your body is made up of many, many cells that are so small you can only see them with a microscope. We need these cells to live. Cancer cells do not look or work like normal cells, and grow very fast. Cancer cells crowd normal cells, and make a tumor (mass or lump). The cancer will make the normal cells unable to work right and may make the person sick. Cancer cells can spread to other areas of the body. They can also grow in places where they do not make a tumor, like the bone marrow.

Chemotherapy: Also known as ‘chemo’. This is a special medicine given to kill the cancer. It can be given as a pill, needle or in the vein. It can cause side effects, such as hair loss.

Cure: When no signs or symptoms of the disease have been present.

Hematologist: A doctor who has special training/education in treating diseases in the blood.

Hematology: The study of blood and blood forming tissues.

Oncology: The study of many types of cancer.

Oncologist: A doctor with special training/education in diagnosing and treating many types of cancer including medical oncologists, radiation oncologists and surgical oncologists.

Prognosis: This is a prediction of how the cancer will respond to treatment and predicts how long and well a person can live.

Radiation: A type of cancer treatment using special, high energy, x-ray beams to kill cancer cells. It is given by a machine, in small doses, over a number of days. It is usually given to the part of the body affected by cancer.

Recurrence: The return of the disease after the patient has been in complete remission

Relapse: When cancer comes back after it has been in a remission.

Remission: When the cancer has disappeared, and there are no cancer symptoms, after treatment.

Side Effects: Problems that are caused by the treatment. It can be many different things – like being tired, having an upset tummy, throwing up, loosing your hair (temporarily), getting an infection and others.

Surgery: A procedure performed by doctors, called surgeons, who have special training/education in doing operations.

Transplant: A special treatment used for some cancers. It is used to let the patient get intense doses of chemo and sometimes radiation; and then giving the person back a new immune system to help fight the cancer.

Being informed and
understanding your illness
is so important. If you don’t understand just
ask your health care provider



Understanding the developmental stages

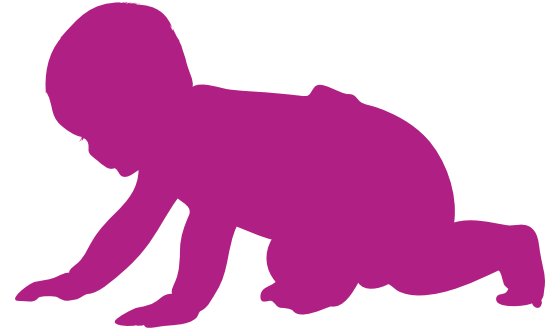
It is important to note that ALL children grow and develop at their own pace. Remember as we learn about the developmental stages and milestones that each child is different. Please use this only as a guide. Remember you know your child best!

Infants & Toddlers (Birth-3 years)

Understanding Reactions

They will understand the change in their routine and are likely only concerned about how it will affect their life.

Babies and toddlers may show signs of regression such as bedwetting or wanting a bottle instead of a cup. Often this is temporary as it is a way for the child to feel familiar and safe. This is why a calm, familiar routine is so important especially during this time.



What you can do!

- Try to keep their routine as consistent as possible. A predictable calm routine is very important for this age group.
- Purchase a journal - If you have a family member helping you or even caring for your child you might want to record the daily routines for the caregiver in a journal and have the caregiver record important issues or developments of your child.
- With technology enhancement in larger centers most hospitals have internet access. Be sure to ask what they have available to keep you as connected as possible to your baby or toddler. Use skype or facetime for example, to stay connected.
- Remember to use simple language for example "daddy is sick" or "daddy has a boo boo".

Notes





Preschool Age (3–5 years)

Understanding Reactions

Young children often do not understand the extent of an illness but can still identify tensions and changes in the home.

The preschool age child often expresses her/his feelings through play or mood rather than in words.

S/he may believe the illness is contagious and have fears that they or other family member will become ill.

Preschool age children are visual learners.

This age may require repeated explanations.



What you can do!

- Be cognizant of acting out behaviors as if they may be ways your preschool child is expressing themselves.
- If your child is in a day care, has a babysitter, or is in preschool, ensure that your childcare provider is aware of what is happening so they can continue to support your child.
- Try to have some one-on-one time with your child.
- Remember to use simple language; however, using the word cancer is important.
- You can also use puppets or dolls to help explain what is happening to mommy or daddy.
- Purchase an activity book (list at the end of the guide) to allow your child to express her/himself. MAKE IT FUN!
- Physical activity is also a great way for this age group to express themselves.

Notes





School Age (5-12 years)

Understanding Reactions

School age children or young teenagers may seem to be more articulate but often they are less forthcoming with their emotions.

They will better understand and appreciate details of the illness more than a preschool aged child. This age group will likely be more inclined to ask questions about the illness, procedures and treatment. Being prepared is important.

They may need extra support around their coping or anxiety.

They may exhibit their anxiety with physical symptoms

What you can do!

- Presenting clear information to this age group is vital.
- Share information about your health issues with school administration or classroom teachers to be sure that they can monitor your child.
- Communication is key with your child!



Notes





Adolescence (12-16 years)

Understanding Reactions

Being a teenager can be a time of emotional ups and downs. Teenagers can feel confused and unsure about themselves. This can make their response and their coping with a parent's illness very different.

Although this youth of age share a lot of the same communication needs as the school age stage, the teenage years are also a time to establish independence, which can create challenges in asking for help.

Teenagers are likely to seek their friends for support.

What you can do!

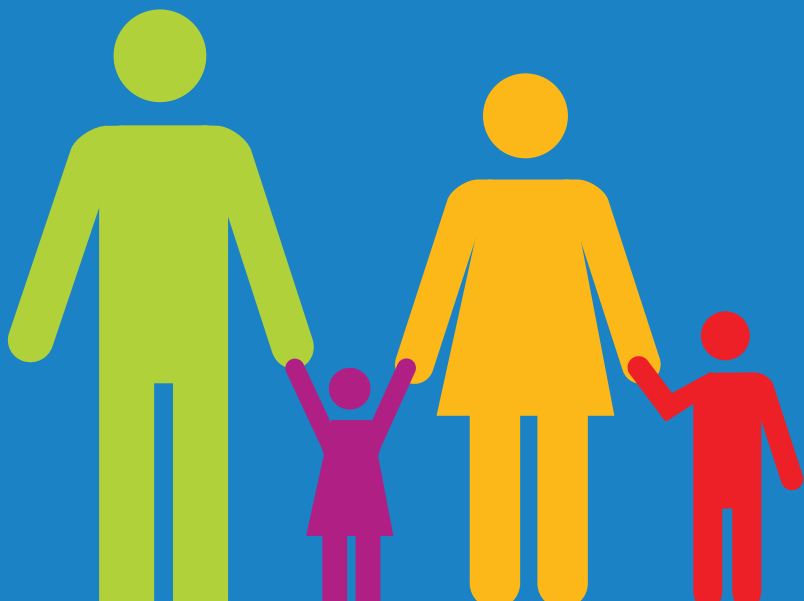
- One of the most important things that you can do to support your teenager is to tell the truth! Provide as much information as deemed appropriate, depending on your child.
- Encourage your child to express their feelings. It is very important that they be included in what is happening.

Notes





Tell your child
“I am doing **everything** I can
to get better and have the
best **doctors helping me**
so I can live as long as possible.”



Reassuring your child is important.

As always, show your child a lot of love and affection. Remember that you are the EXPERT on your child. Cancer can be overwhelming and disruptive, but it doesn't change the fact that you know your child best.

Preparing children for their visit to the hospital

- Explain to your child what to expect including what they might see or hear.
- Advise your health care team of the anticipated visit.
- Have their photos in your room or even a special blanket depending on your child's age. This could be comforting to your child.
- Most importantly, allow for privacy and alone time with your child.

One way to help your child
stay connected during your
hospital admission
is allow them to draw
pictures for your room.

Preparing for the WHAT IF conversation

What if your child asks if you are going to die?

This question sparks immediate anxiety for parents when planning to talk to their children. Often children associate Cancer with Terry Fox whom they have learned about

in school, which can trigger this question and thought process with their connection to dying. This is why parents are encouraged to explore past experiences with cancer.

There are many responses that you can provide to this particular question. You need to answer this question to what is comfortable for you and your family. Again, understanding your child's development and past experiences is key in planning how you might respond to or address this particular question.

A few key points:

- Tell your child that people do die from cancer but there are special treatments/medicines out there to help people live for a long time.
- It is important not to give false hopes to your child if your prognosis is poor. This is a conversation that would be encouraged with your health care team and family as to how to address this news to your child.
- Consistency is essential between parents and family members in your response to this question and how the conversation continues throughout your journey.

What IF you cry?

Remember talking to your child as mentioned earlier is a very difficult conversation to have. It is perfectly okay to cry. Your child and family will see that it is okay to express their emotions and feelings. Crying often gives your child and family permission to cry as well.

How you address your emotions will depend on your child's age. For example, if you have a young child you might want to tell them you are sad because you have to be in hospital and that it is not their fault.

If you have a teenager your response to being tearful maybe a little different depending on how you are feeling and what you feel is appropriate to share with them.



Notes ● ● ● ● ●

Lined area for taking notes.

What if you don't have an answer to your child's question?

Not having an answer to your child's question is another fear that parents face. Use your health care team if your child asks medical questions. It is also okay not to have a response. You may not have an answer yourself! So, reassure your child you will get the answer to their question before you let them know. There may be times that your medical team may not be able to answer all the questions either but be as honest as possible. You can also write down some of the questions your child may have so that you can ensure that you remember to ask your health care team.

How you can support your child during this time?

Minimize Disruption

Minimizing disruption in a child's life and routine is very important during this time, however, this may be unavoidable. There are ways that you can minimize the disruption as much as possible.

- If your child is school age this plays a vital factor in keeping their routine as normal as possible. Ask another parent of a child in the class to help you if needed to do so.
• Maximize family time to what is realistic for you and your family.
• Phone calls may increase within the home, setting boundaries is important.
• Place a sign on the door of your home or hospital room advising friends and family of visiting hours. Encourage your family to call before they visit.
• Reach out to family. Use the next section to help you.

Reach Out!

Use the following page to document your list of family member names and telephone numbers and their availability. Think about the strength of this person and the connection they may have with your child. Is there an uncle who enjoys hockey and would love to take your child to their Saturday game? Is there someone who can cook your child's favorite meal when you may not be feeling up to it? Completing the table could ease your stress in times where childcare may be an issue or you require additional support. Most families are more than willing to provide support if you ask them. This will also act as an excellent communication tool for the family.

Make arrangements with them now so that if you need them they will be aware and can offer the support or assistance. This will relieve a lot of anxiety and stress.

Honest communication is key.



Name	Phone Number	Availability
<i>Uncle John</i>	<i>123-4567</i>	<i>Off work on Saturdays and has agreed to take Sam to Hockey.</i>

Social Workers can provide counselling to individuals, couples, families and groups to improve coping and help you find HOPE! Reach Out!

Strengths

Take some time to reflect on YOU! This guide has been about your concern for your child and what you can do. This speaks to the strength of you as a parent. Take a few moments and think about the strength that you have as an individual to aid in your fight of cancer and write it in the circle. I hope this will help you along your journey!

Refer back to this when you have a difficult day to remind yourself how **resilient & strong** you can be!



Resources

Suggested Books For Preschool Children (Ages 2 – 5 years)

Sammy's Mom Has Cancer

Author: Sherry Kohlenberg, 1993

Author Sherry Kohlenberg wrote this book to help her son understand what was happening to her following her diagnosis with cancer.

The American Medical Writers' Association voted it Best Book of 1994

When Mommy Loses Her Hair

Author: Cristen Cervellini-Calfo, 2008

A story of a 4-year-old boy Tony who hears his parents talking about his mother's cancer. Tony's dad helps him understand cancer and how it will impact their family.

Suggested Books For School-Age Children (Ages 5 – 10 Years)

Butterfly Kisses and Wishes on Wings

Author: Ellen McVicker, 2006

A story about how a young boy learns about his mother's cancer diagnosis and finds hope and strength. Beautiful story and illustrations.

Mom has Cancer

Author: Jennifer Moore-Mallinos, 2008

The story of a little boy who shares his feeling of his mom's cancer diagnosis throughout her journey. It encourages parents to be open with their children.

The Rainbow Feelings of Cancer

Authors: Carrie Martin & Chia Martin, 2001

Invites children to share their thoughts, feelings, and questions when a life-threatening illness has touched a parent or someone they love.

Our Mom Has Cancer

Authors: Abigail & Adrienne Ackermann, 2001

Two sisters ages 11 and 13 describe what it was like for them when their mother was diagnosed with breast cancer.

Becky and the Worry Cup

Author: Wendy S. Harpham, M.D., 1997

Six year old Becky has many adjustments to make and new feelings to deal with when her mother is diagnosed with cancer.

Promises

Author: Elizabeth Winthrop, 2000

A young girl's experience with her mother's cancer treatment, including her desire to have her mother promise the cancer will never return.

Because Someone I Love Has Cancer

Author: Alaric Lewis, 2005

A Guide to Help Kids Cope

Because Someone I Love Has Cancer: Kids' Activity Book.

Author: American Cancer Society, 2003.

A journal for kids ages 6–12 with lots of drawing and writing suggestions.

Time for Me: An activity book for kids when someone in the family has cancer.

Author's: June Slakov. & Karen Janes. (2004).

A workbook for school age children. It helps encourage children learn about cancer and express their feelings.

Suggested Books For Pre-Teens and Early Teens (Ages 10 – 14 years)

Can I Still Kiss You?

Author: Neil Russell, 2001

A question and answer format is the basis for the book dealing with questions frequently asked by children and adolescents.



The Year My Mother Was Bald

Author: Ann Speltz 2002

Written as a diary from a 13 year old girl's perspective during the year her mother went through cancer treatment.

Suggested Books For Teens (Ages 14 and older)

Both Sides Now

Author: Ruth Pennebaker, 2000

A novel about family dealing with breast cancer and their child's anger and fears.

My Parent Has Cancer and It Really Sucks

Author: Maya Silver and Marc Silver, 2013

Real life advise written by real life teens.

Suggested Books For Adults

When A Parent Has Cancer. A Guide To Caring For Your Children.

Author: Wendy Schlessel Harpham, M.D

A guide which provides practical advise to parents who have been diagnosed with cancer.

Raising an emotionally healthy child when parent is sick.

Authors: Paula Rauch, & Anna Muriel, 2006

From experts at Harvard Medical School this book helps understand a child's perspective.

How to Help Children Through a Parent's Serious Illness

Author: Kathleen McCue, 2011

Provides guidance for parents on supporting their children and helping them cope with the many challenges and changes illness brings.

Websites you may find helpful

BC Cancer Agency: www.bccancer.bc.ca

Canadian Cancer Society: www.cancer.ca

Cancer Council Australia: www.cancercouncil.com.au

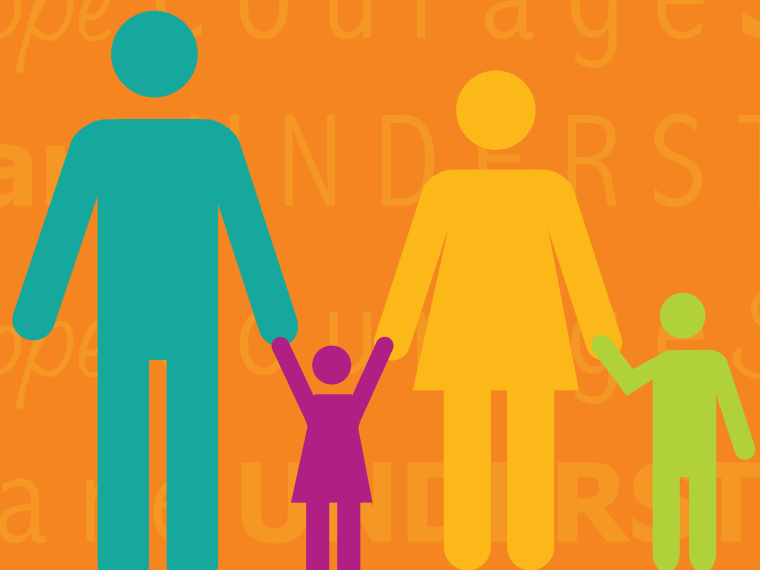
Livestrong Foundation: www.livestrong.org

Marjorie E. Korff Pact Program: www.mghpact.org

Young Adult Cancer Canada: www.youngadultcancer.ca



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care **UNDERSTANDING** love c



Your feedback is important!

1. Age: _____ 2. Gender: Self identify: _____ 3. Diagnosis: _____

4. How did you find out about this guide?

- Health care provider
- Another patient
- Online
- Other (Please comment) _____

5. How long following your diagnosis did you obtain this guide?

- 0-1 month
- 1-2 months
- 2-4 months
- 4 months or more

6. Did you find the guide helped in preparing to talk to your child (ren) about cancer?

Strongly agree		Agree		Neutral		Disagree		Strongly disagree
1	2	3	4	5	6	7	8	9

7. Did this guide help you facilitate a conversation with your child(ren)?

Strongly agree		Agree		Neutral		Disagree		Strongly disagree
1	2	3	4	5	6	7	8	9

8. Would you recommend this guide to others?

Strongly agree		Agree		Neutral		Disagree		Strongly disagree
1	2	3	4	5	6	7	8	9

Please comment: _____

Please provide to your health care team to submit evaluation to Bonnie Hobbs • bonnie.hobbs@easternhealth.ca





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