

# YOU HAVE CANCER.

Now you have to  
tell your children.



## When a Parent Has Cancer

EDUCATIONAL GUIDE FOR EVERYONE IN THE FAMILY

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# Introduction

At Wellspring, we recognize that a cancer diagnosis affects the entire family. If you, or someone else in your family has been diagnosed with cancer, you may be wondering how you should handle this with your children.

Many questions come up for parents:

- Should we tell our children?
- Should we use the word 'cancer'?
- How do we go about sharing the information in an age appropriate way?
- What if they ask us questions to which we don't know the answer?
- How should I expect them to react when they find out?
- How do I support them when I am struggling with my own emotions?

This booklet will help you prepare by offering best practices and good advice on how to talk with, and provide support to, your children.

In addition to this booklet, Wellspring can offer you access to professionals who specialize in family support.



# Telling the Children



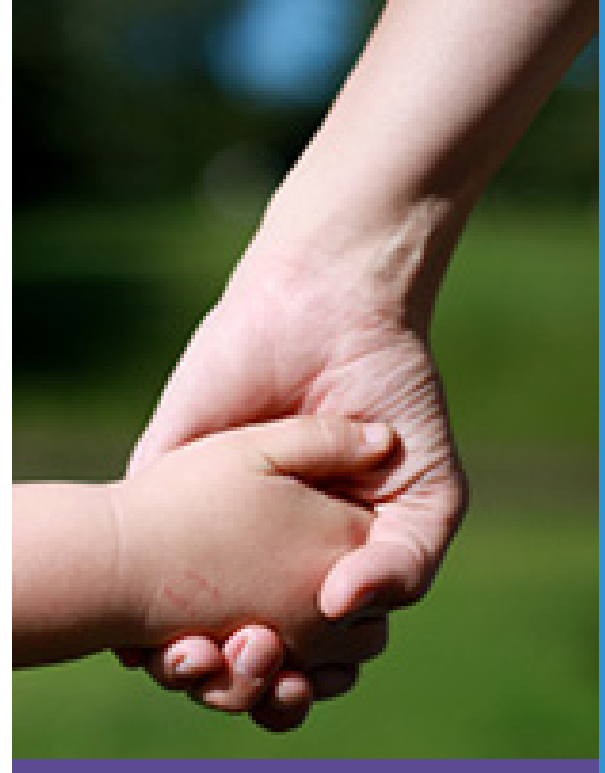
## Why do parents hesitate to tell their children about a cancer diagnosis?

"I want to protect them."

- One of our main responsibilities as parents is to protect our children. We worry that telling them that their parent has cancer will cause them to worry and feel sad. This concern is even greater if your children have struggled with anxiety or have other concerns in their lives.

"My children know about cancer and that it is life threatening. I don't want to worry them unnecessarily."

- From the time children enter school, they often know the word 'cancer' and that it is life-threatening. Parents may worry that the word 'cancer' will bring up questions or concerns about death. When parents are concerned themselves about their own future and unsure about the outcome of their treatment, they are often unclear about how to support their children when they don't have definite answers to their questions.



## Then why tell them?

"After I told my daughter, she told me she knew something was wrong before I told her."

- Children (even very young children) will often have a sense when something is "off". They may not initially know what it is, but they will pick up on tension, whispered voices, or facial expressions of their parents.
- Treatment such as chemotherapy, radiation or surgery will mean changes in family routines and many absences from the home that will be noticed. Treatment may result in side effects that will often be visible or noticed by the children.
- Parental cancer impacts their children's lives. They may need to have different people taking them to sports or school. Relatives may come to stay.
- The ill parent may not be able to do all the things they normally do. This can be confusing for the children if they do not understand why.
- Sometimes parents use other language to avoid the word cancer. Words like "sick" or "boo boo" can lead children to assume it is like other illness such as colds, the flu or scrapes which they get too, some of which are contagious.
- Although sharing the diagnosis does indeed bring up worries and concerns, it also opens a door for communication and discussion so that children to identify and talk about their feelings.
- Children tell us that although they wish their parent did not get cancer in the first place, they are glad they have been told and included in something that affects their world. This is shown repeatedly in both the research and through our experience.



## How do I tell them?

- Prepare by talking about it with another adult first. Doing so allows you to rehearse difficult parts and express your feelings while not in their presence. It also helps to problem solve about how you will handle difficult questions.
- Set aside a time when you will not be interrupted. If you have a partner, share the news together.  
It is best to tell the children yourself if you are able. If it is too difficult, have your partner or another close adult tell them with you present. It is usually a good idea to share the information with the whole family present. Individual needs or questions can be dealt with separately.
- Use basic language to describe what is happening and keep it brief.
- Identify that it is cancer and what kind of cancer. For example, "I found out today that I have a type of cancer that is in the blood. It is called leukemia."
- Young children may need to be told what cancer is. A good description for little ones is to explain that our bodies are made up of cells and that usually cells do what they are supposed to do and keep us healthy. But, sometimes cells get all messed up and grow out of control and cause us to be sick. When that happens, it is called 'cancer'.
- Identify what the next steps are for treatment. For example, "Mommy will have to go for a surgery to get the cancer out. After that she will need to get some medicine called chemotherapy to make sure that they got all the cancer."
- Tell them how this will impact their lives specifically. For example, "Because Mommy has to go for treatment, Grandma is going to stay with us and help us before and after school."
- Ask them if they have any questions. Let them know there are no bad or stupid questions and that sometimes they might think of questions later and that they can talk about it at any time.
- Allow them to do what they need after they learn. Some children may cry and become quite upset and then need to go off and do something to distract themselves. Others may be clingy, while others need to be alone. There is no right or wrong way for them to behave. Allow them to choose it and be supportive of that choice.
- Parents tell us that usually children react in a way that is in keeping with what parents would expect from that particular child. For example, if a child typically reacts in a "big" way to difficult news or change, then they usually do this when learning about the diagnosis. A child who typically reacts by becoming quiet and withdrawing usually does this. There is no "right way" to react, only what comes naturally to the child.

## How much information do they need?

- The amount of information or detail needed depends on the age and developmental stage of the child and also on their personality.
- All children benefit from knowing that: a) it is cancer, b) what kind of cancer it is and what to expect regarding treatment and c) how it will affect their lives directly.
- Let them know that there is nothing that they did to cause the cancer and that it is not contagious in any way.
- Some children will be very inquisitive and may want detailed explanations about cancer. It is best to allow for these questions and to answer them as honestly as possible. If they ask questions you don't know the answer to, you can offer to look into them or ask your doctor the next chance you get, and that you will let them know the answer at another time. It can help to have a pad of paper to write the questions down so they see you making note of them.

## What if they ask me if I will get better or even if I am going to die from cancer?

- Parents tell us this is the number one fear that they have about sharing the diagnosis with their children.
- It is normal for children to wonder and worry about this.
- The goals of answering this question are: a) be honest, b) stick to what you know, c) discuss what to hope for, and d) if you can, ask them what they think about or feel when they think about it.
- Examples of possible responses:
  - For an early stage cancer you might say "Some people do die from cancer, but the doctors have told me that they feel pretty sure that we can get rid of it. I will do everything I can to get rid of the cancer and I feel hopeful that I am going to be OK. I promise I will tell you if I am getting better and even if something isn't working ... I will let you know, no matter what."
  - For a more advanced cancer you might say: "I have a type of cancer that it is hard to get rid of. All of the things I am doing are trying to shrink the cancer and make it smaller, or at least keep it from getting bigger. I am hoping that I can live with this cancer. I can let you know if it is growing or changing so that you will know. When you think of Daddy dying from cancer, do you feel sad or scared?"
- When the cancer is terminal and progressing, please refer to **"Helping Children Cope when a Parent has Terminal Cancer"**.

# Family Member “Cheat Sheet”: Talking with Your Children

We have included this Family Meeting “Cheat Sheet” to help summarize and simplify steps for you to follow as you share the diagnosis:

1. Prepare for the talk with your partner, or another trusted adult. Decide how and when you will talk to your children. Let yourself feel the feelings that come up as you talk so that you feel more relaxed when you talk to your children. It is OK to be emotional when talking to them but try to avoid them needing to comfort you or shield you from their feelings.
2. Don’t worry about following a script. Just be yourself. Roleplay first if you feel unsure about how to word it.
3. Choose a quiet place for your family to meet and at a time when you are not rushed or interrupted.
4. Remember to name the cancer, explain briefly what it is, tell them how it will impact them and encourage them to ask questions.
5. Watch for signs that your children have had enough. Long conversations may challenge your children’s attention span, and may be overwhelming in content. It may be better to have a series of shorter conversations that keep your children’s attention and do not cover everything at once.
6. Pace yourself, include lots of pauses, check in with them and offer lots of tender loving care.
7. Remember to tell them that you will keep them up- to- date no matter what – it goes a long way in establishing trust and assuring them that the communication will be ongoing and a two-way street.





## Understanding and Helping Our Children

### What should we expect to see from our children?

Generally speaking, children will show a level of understanding and behaving that is in keeping with their age and development.

#### **Babies and Toddlers:**

- Have no understanding of cancer or illness
- May notice changes in routines or reactions from close people in their lives
- May show frustration through tantrums or acting out
- May be erratic for a period of time regarding eating and drinking
- May react with anxiousness when separated from their parent.

**Pre-schoolers:**

- Likely do not have an understanding of cancer
- May not understand the difference between a mild illness like a cold, and a serious illness like cancer
- May “forget” that you told them about your illness and need you to tell them frequently or re-ask questions they have already asked
- May react with anxiousness when separated from their parent
- May use play or acting related to illness to express themselves
- May regress somewhat; e.g., if toilet trained, may wet the bed
- May think cancer is contagious.

**School age:**

- Likely know generally about cancer as a term but may not understand what it is
- May make the assumption that cancer is terminal or curable based on their own experiences; e.g., if only know about Terry Fox, may assume people die from cancer, or, if they had an aunt with cancer who is well now, may assume it is curable
- May think that it is something that they did that caused it or that they can cure it with their behaviours or thoughts (this is called magical thinking)
- May react with anxiousness when separated from parent
- May show anxiousness about attending school
- May show regression; e.g., more frequent mood swings or temper tantrums
- May not be able to identify or say how they feel in words but may show it through play or art
- May be embarrassed about their parents cancer; e.g., if parent is bald because of the attention that it brings from others, or makes them feel different than their friends
- May worry about both the parent who is ill and also worry that the well parent may get sick.

**Teens:**

- Most know basically what cancer is but may still have misconceptions about it
- Likely do not know in detail about cancer but is capable of understanding it
- More likely to look toward the internet for information about your diagnosis
- May have concerns about life and death and how the family would manage
- Feel caught and confused between the process of becoming independent and being pulled closer to the family because of the illness
- May react to additional responsibility that falls to them due to their parent’s illness
- May take out frustration and anger on family members
- May have difficulty identifying and expressing emotions.

# How can we best support our children?

## 1. Routines and Rules:

- At the time of diagnosis and the months that follow, routines may alter drastically and it may be challenging to maintain consistent rules that run the house.
- Children benefit, however, from as much consistency as possible, and knowing what to expect.
- Do the best that you can do to maintain a sense of stability at home and activities. For example, you may not be able to take your child to hockey practice but they can still attend practice and know who will take them, do up their skates, etc.
- Allow children to help as much as possible. It can feel good for kids to do things at home that make a difference. Activities should be limited and age appropriate. It is tempting to view a teen as another adult in the home when roles are shifting but be aware of the signs that they are being overburdened with new or changing responsibilities. Even children who really want to do a lot may not realize that it is having an adverse affect on them.

## 2. Encourage communication and expression of feelings

- It is a challenging time for children and they may have difficulty identifying and expressing their emotions.
- You can help them by being a role model and talking about your feelings are how you are handling them. For example, "I am worried sometimes but then I try to focus on the fact that the last time I had a test, it showed that the cancer was smaller than before."
- Encourage open communication and avoid asking questions that can be answered with a "yes" or "no" response. For example: What were you thinking about as you lay in bed and can't sleep?" encourages more open communication than "Did you lay in bed last night and not sleep?"
- Try not to switch too quickly into problem solving when your child is talking about a thought or a feeling with which they may be struggling. Instead, ask questions about it, explore it, and help them find the words to talk about it.





### **3. Let them know who in their lives knows about the cancer and can support them**

- It is recommended that at least one individual at your child's school know about your cancer, such as the child's teacher or principal. That person is your eyes and ears at school, can support your child when you are not there and can alert you if they see any behaviours that are out of the norm.
- Let your child know who at school they can talk to and let them decide with you how involved they want that person to be. For example, "I don't mind if my teacher knows but I don't want them asking me all the time about it".
- There may be other adults who are close to them that they can open up to about the diagnosis and how they feel. Identify those other adults with your child.
- Help them explore if they would like their friends to know about it and, if so, how they would like to tell them.
- They may be interested in reading or watching a movie or visiting a website that talks about parental cancer.

## **What do I do if my child seems to be really struggling?**

Parents often struggle with knowing when their child may need additional support on top of what you are offering at home. As noted, most children will demonstrate changes in emotional responses, behaviours and routines and may regress especially at the time of diagnosis. Often children will "bounce back" over time and learn new ways of coping. Some signs your child may need additional support are:

- Struggling at school when they have not typically been struggling
- Extreme changes in behaviour such as acting out, not sleeping well or sleeping too much, drastic change in eating, isolating themselves.
- Showing a lack of interest in activities they used to like.
- Children who have struggled with emotional wellness or experienced behavioural issues prior to the diagnosis may show an increase in these areas, and parents and children may need additional support strategies.
- Any sign or indication that they may hurt themselves or someone else (in which case, parents should seek immediate medical/mental health support through their family doctor or hospital).



## How can Wellspring help our family?

Many families reach out for help when they are first diagnosed, others as they are further along in their treatment or recovery. Wellspring is here any time to help you, or your children, with cancer support needs.

Wellspring offers a full range of support, coping, educational and health restorative programs for the parent with cancer, their partner and other significant caregivers. For more information about all of the programs available, please visit [wellspring.ca](https://wellspring.ca).

# Family Counsellor

Wellspring offers specialized Family Counsellors, trained to help families with respect to a parent's illness. The Family Counsellor can provide you with short-term counselling to help you to prepare for talking with your children, support your family's unique needs and ensure you have ongoing support for you and your children. After a referral is made to the Family Counsellor, we aim to have someone contact you within one business day to arrange a time to meet at Wellspring. In the event you or your family need longer term support, the Family Counsellor can help make a referral to a community support service best suited to your needs.








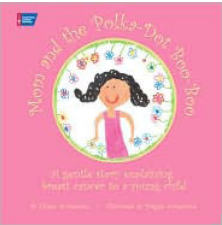
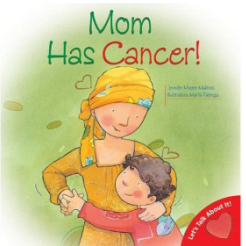

## Children's and Parents' Program




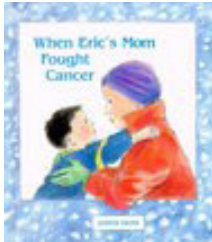

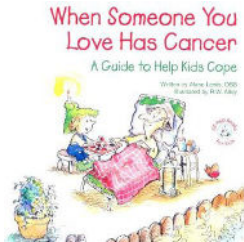
Wellspring offers an 8-week Children's and Parents' Program that brings parents and their children together for family time, networking, conversation about having cancer in the family, and tools to help them cope and express how they are feeling. Children will learn that they are not alone and will be guided by two professional leaders through various topics using age-appropriate communication and therapeutic play activities. While children are together, parents meet separately to address the same topics so that they can continue the conversation, and support of their children, at home.

To register, or for more information, visit the Children's and Parents' Program section in your local Wellspring centre on the website.

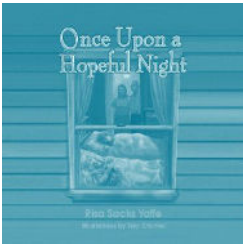


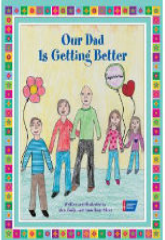

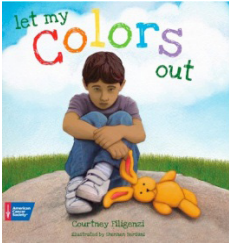
# Suggested Reading List and Online Resources

## Books

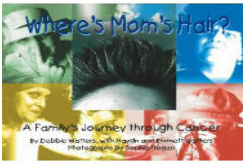


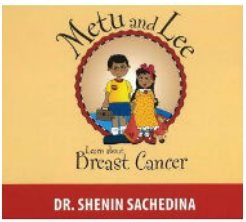

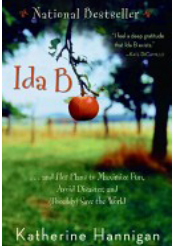
	<p><b>Sammy's Mommy has Cancer</b></p> <p>By Sherry Kohlberg</p> <p>This is a gentle, sensitive story for young children dealing with a parent's cancer. Includes activities for the family to do before, during and after treatment.</p>	<p>Ages 2-8</p>
	<p><b>Mom and the polka-dot-boo-boo: A gentle story explaining breast cancer to a young child.</b></p> <p>By Eileen Sutherland</p> <p>An informative and reassuring story, this book helps families talk about breast cancer, gently preparing children for what lies ahead in the weeks and months following their mother's diagnosis.</p>	<p>Ages 3-8</p>
	<p><b>Mom Has Cancer</b></p> <p>By Jennifer Moore Mallinos and Martin Fabrega</p> <p>This book is about a young boy's worries before learning about his mom's cancer and the changes he and his family go through when they communicate openly and honestly. A simple, clear book for young children.</p>	<p>Ages 3-8</p>
	<p><b>My Daddy's Cancer</b></p> <p>By Cindy Klein Cohen and John T. Heiney</p> <p>A simple but good book for young children. A young child asks questions about the father's cancer e.g. Did I cause him to have cancer? Addresses serious illness, hospitalization. Includes activities. Also includes a helpful section about talking to your children about cancer.</p>	<p>Ages 3-8</p>

	<p><b>My Mommy's cancer</b></p> <p>By Cindy Klein Cohen and John T. Heiney</p> <p>Exactly the same book as My Daddy's Cancer listed above, but in this one the mother has cancer.</p>	<p>Ages 3-8</p>
	<p><b>My mommy has breast cancer but she's o.k</b></p> <p>By Keri M. Conner</p> <p>A colourful, simple book for children when mom has breast cancer.</p>	<p>Ages 3-8</p>
	<p><b>Promises</b></p> <p>By Elizabeth Winthrop</p> <p>This story deals with Sarah and her emotional journey through her diagnosis of cancer, hospital stays, chemotherapy and her hair falling out. Also deals with the idea of not making promises we can't keep.</p>	<p>Ages 3-8</p>
	<p><b>When Eric's Mom Fought Cancer</b></p> <p>By Judith Vigna</p> <p>Follows a little boys' journey through the experience of his mother's cancer. Deals with the symptoms of cancer and its treatments, including hair loss, fatigue and change the parental role.</p>	<p>Ages 3-9</p>
	<p><b>When mommy had a mastectomy</b></p> <p>By Nancy Reuben Greenfield</p> <p>This book deals with a mother's breast cancer, her surgery and reconstructive surgery and how she tries to get back to living life "normally".</p>	<p>Ages 3-9</p>
	<p><b>When Someone you love has cancer: A guide to help kids cope</b></p> <p>By Alaric Lewis</p> <p>A good book for providing an overview of how children cope when someone they love has cancer. Describes the different emotions they may experience and provides over 40 "pointers" designed specifically for children to help them cope.</p>	<p>Ages 3-9</p>




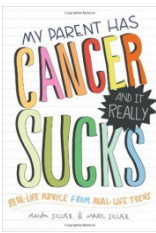
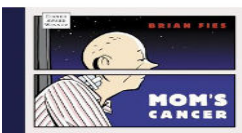


	<p><b>Once Upon a Hopeful Night</b> By Risa S. Yaffe</p> <p>A book for pre-school and school age kids whose parents have cancer. Written in verse.</p>	<p>Ages 3-10</p>
	<p><b>Because . . . Someone I Love Has Cancer: Kids' Activity Book</b> By the American Cancer Society.</p> <p>This activity book uses artwork and activities to allow children to express themselves about cancer.</p>	<p>Ages 3-12</p>
	<p><b>Butterfly kisses and Wishes on Wings. When someone you love has cancer.</b> By Ellen McVicker</p> <p>This is a listen-to or read-aloud book for children. This story is told from a child's view about their mother's cancer, and provides a simple and clear understanding of cancer. Also the author has an excellent website: <a href="http://www.butterflykissesbook.com/beabutterfly.html">http://www.butterflykissesbook.com/beabutterfly.html</a></p>	<p>Ages 3-12</p>
	<p><b>Our Dad is Getting Better</b> By Alex, Emily and Anna Rose Silver</p> <p>This is a story written by children about a father with cancer who is now recovering from it. It deals with survivorship issues including the possibility of recurrence.</p>	<p>Ages 4-up</p>
	<p><b>Tickles Tabitha's Cancer-tankerous Mommy.</b> By Amelia Frahm</p> <p>A sweet story about a young girl whose mom has cancer. Deals with chemotherapy and hair loss.</p>	<p>Ages 4-10</p>
	<p><b>Let my colours out</b> By Courtney Filigenzi and Shennen Bersani</p> <p>The story of a young boy's journey as his mother undergoes treatment for cancer. The boy uses colors to express a range of emotions throughout the process of coping with his mother's illness.</p>	<p>Ages 4-12</p>

	<p><b>Our Mom has cancer</b></p> <p>By Abigail and Adrienne Ackerman</p> <p>Two sisters, ages eleven and thirteen, describe what it was like for them when their mother was diagnosed with breast cancer and underwent surgery and chemotherapy.</p>	<p>Ages 4-12</p>
	<p><b>Talking to my Treehouse Friends about Cancer</b></p> <p>By Peter R. van Vermoot</p> <p>An activity book about cancer which allows children to be creative doing activities while learning about cancer. They suggest ages 9-12 are best suited for this book but we would suggest all school-age children would benefit from it e.g 4-12.</p>	<p>Ages 4-12</p>
	<p><b>The Hope Tree: Kids talk about breast cancer</b></p> <p>By Laura Numeroff and Wendy Harpman</p> <p>This story uses different animals as characters who narrate their personal stories dealing with breast cancer. The characters range from 5-12 years old.</p>	<p>Ages 4-12</p>
	<p><b>The Paper Chain</b></p> <p>By Claire Blake, Eliza Blanchard, Kathy Parkinson</p> <p>This story is about a family's experience when their mother is diagnosed and hospitalized during cancer treatment.</p>	<p>Ages 4-12</p>
	<p><b>The Year my mother was bald</b></p> <p>By Ann Speltz</p> <p>A young girl talks about her feeling and experience when her mom is diagnosed with cancer, including treatment from chemotherapy, surgery, and radiation. Helps to explain cancer and its treatment and validates their emotional experience.</p>	<p>Ages 4-12</p>
	<p><b>The Rainbow Feelings of Cancer</b></p> <p>By Carrie Martin and Chia Mach</p> <p>When a young girl's mother gets cancer, she experiences a lot of different emotions. Provides a good overview of the emotions a child goes through over the course of a parent's illness.</p>	<p>Ages 4-12</p>

	<p><b>Where's Mom's hair? A Family's journey through cancer</b></p> <p>By Debbie Watters</p> <p>When a boy's mom gets cancer, the family and community come together to support her. Deals with chemotherapy and hair loss, as well as looking to others for support.</p>	<p>Ages 4-12</p>
	<p><b>You are not alone: Families touched by cancer</b></p> <p>By Eva Grayzel</p> <p>This book tells the stories of children from around the world who have cancer.</p>	<p>Ages 4-12</p>
	<p><b>Becky and the Worry Cup</b></p> <p>By Wendy S. Harpham M.D.</p> <p>This book tells a story of a seven-year-old girl's experiences with her mother's cancer. It is included in the parent's book "When a Parent Has Cancer".</p>	<p>Ages 5-12</p>
	<p><b>Metu and Lee Learn about Breast Cancer</b></p> <p>By Dr. Shenin Sachedina</p> <p>Metu and Lee's mother has been diagnosed with breast cancer. The book discusses surgery, chemotherapy, radiation, and child's fears and good and bad cells.</p>	<p>Ages 5-12</p>
	<p><b>Our family has cancer too</b></p> <p>By Christine Clifford</p> <p>When their mother is diagnosed with cancer, sixth grader Tim and his younger brother visit her in the hospital, learn about radiation and chemotherapy, and help with the chores at home.</p>	<p>Ages 7-12</p>
	<p><b>Ida B: and Her Plans to Maximize Fun, Avoid Disaster and (Possibly) Save the World</b></p> <p>By Katherine Hannigan</p> <p>A funny and sensitive story of a grade four girl whose mother gets cancer.</p>	<p>Ages 8-up</p>



	<p><b>What's up with Bridget's Mom? Medikidz Explain Breast Cancer</b></p> <p>By Kim Chiman-Blair and John Taddeo</p> <p>Set up like a comic book presentation. Superheroes are used to explain about cancer and treatment. This book is best suited for tweens and young teens.</p>	<p>Ages 9-up</p>
	<p><b>Will I Get Breast Cancer? Questions and Answers for Teenage Children of Cancer Patients.</b></p> <p>By Carole Vogel</p> <p>Not just for teens. This book is suitable for all girls and women from 9 –up. Addresses many questions and concerns about breast cancer in a clear, concise way.</p>	<p>Ages 9-up</p>
	<p><b>When Your Parent has cancer: A guide for Teens</b></p> <p>By National Cancer Institute, 2005</p> <p>Download for free from:  <a href="http://www.cancer.gov/cancertopics/When-Your-Parent-Has-Cancer-Guide-for-Teens/PDF">http://www.cancer.gov/cancertopics/When-Your-Parent-Has-Cancer-Guide-for-Teens/PDF</a></p>	<p>Ages 12-up</p>
	<p><b>My Parent Has Cancer and It Really Sucks</b></p> <p>By Maya Silver, Marc Silver</p> <p>A book, also a website and a Facebook page at <a href="https://www.facebook.com/parenthascancer">https://www.facebook.com/parenthascancer</a> for teens who have a parent with cancer.</p>	<p>Older teens</p>
	<p><b>Mom's Cancer</b></p> <p>By Brian Fies</p> <p>In this book, the author and his siblings witness and experience their mother going diagnosis and treatment for <u>metastatic</u> lung cancer. Truthful, but still sensitive.</p>	<p>Older teens</p>

For more information and program availability,  
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