Talking to your kids about breast cancer

A guide for parents
Talking To your kids about breast cancer

It is through our Support Saturdays program that I’ve had the pleasure and privilege of getting to know Morgan Livingstone, a fabulous and much-loved child life specialist that we recruited to develop and run the creative activities for our kids and dads. Her energy and enthusiasm is a magnet for the kids and her knowledge and sensitivity a saviour for the parents. While much of her time during Support Saturdays is devoted to the kids and dads, Morgan always lingers afterwards, happy to chat with any of the moms who have questions or concerns or positive observations they want to share. Through Support Saturdays, Morgan is also available to work with families in Toronto in their own homes. This is particularly helpful right at the time of initial diagnosis and during treatment when children are full of questions (or silent fears) about what’s happening.

I’ve learned so much by watching and overhearing Morgan in the past few years. I really believe in her approach and have seen firsthand how children and their parents have benefited from her help. I so wish we could clone Morgan and send her out to families across Canada. While we can’t do that, this booklet is designed to bring some of her insights and helpful tools to families across the country and even around the world.

I hope you find it helpful and we invite any feedback you may have for us about the booklet or about our work in general.

MJ DeCoteau
Founder and Executive Director
Rethink Breast Cancer

I was just 22 when I lost my mom to breast cancer. I was even younger when my grandmother was diagnosed. In other words, I became “aware” of breast cancer at a very young age. But that didn’t mean I knew what steps I should be taking myself to be on top of my breast health.

I went looking for breast health information in my late 20s. At the time, all the brochures I found had a 65 year old on the cover and were pretty drab and medical looking—not very inspiring for a young person. There was an opportunity to build a new breed of breast cancer charity—one that was focused on young women. I gathered together a dream team interested in helping me change the face of breast cancer and launched Rethink Breast Cancer.

A couple years into my new social entrepreneur venture and about 8 months pregnant with my daughter, I met a young woman with breast cancer who had been diagnosed while pregnant with her second child. My pregnancy had been so blissful and easy—I could not even imagine suddenly receiving such news. Over the coming months, as I experienced the joys and challenges of being a new mom, I found myself thinking about how that young woman juggled a young family with treatment for breast cancer. Even though she had extended family in town and financial resources, it was grueling. What about women without much of a support system?

When I returned to work from maternity leave, I was inspired to start our Support Saturdays program for young moms newly diagnosed with breast cancer and their families. Support Saturdays takes place in our sun-filled loft in downtown Toronto. We bring together new moms recovering from breast cancer and give them a chance to share with each other and get professionally facilitated group support from two outstanding psychologists. Meanwhile, the dads/partners are encouraged to come with the kids and participate in organized healthy medical play and expressive arts activities in an adjoining space.

It is through our Support Saturdays program that I’ve had the pleasure and privilege of getting to know Morgan Livingstone, a fabulous and much-loved child life specialist that we recruited to develop and run the creative activities for our kids and dads. Her energy and enthusiasm is a magnet for the kids and her knowledge and sensitivity a saviour for the parents. While much of her time during Support Saturdays is devoted to the kids and dads, Morgan always lingers afterwards, happy to chat with any of the moms who have questions or concerns or positive observations they want to share. Through Support Saturdays, Morgan is also available to work with families in Toronto in their own homes. This is particularly helpful right at the time of initial diagnosis and during treatment when children are full of questions (or silent fears) about what’s happening.

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Talking To your kids about Breast cancer

Introduction

CHILDREN ARE AMAZINGLY resilient. From the day they are born, children are learning constantly by seeing and doing. With the right information, attention and support, children can learn just about anything. They can even learn to cope with Mommy’s breast cancer (diagnosis).

Cancer affects the entire family. As members of the family, children of all ages need to be included as active participants in this situation as much as comfortably possible. Every child will experience the diagnosis in a different way and with different feelings – and there is no right way or wrong way. Each child’s experience is their own experience, and it is your job to support them through it. Remember to seek out help if you need it – from friends, family and your medical team as well as from breast cancer charities such as Rethink Breast Cancer.

This booklet was created to provide information to young women living with breast cancer and their families in a helpful, direct and upbeat way. It includes important points on parenting during illness, how to talk openly and honestly to children of all ages about your breast cancer, and common reactions children may have to this news.

Many families wonder, “When will life return to normal?” Life after a breast cancer diagnosis is the “new normal.” By focusing on the opportunity to share, support and work together as a family, you can grow stronger and closer as you learn to face and meet the challenges of your cancer experience.

Telling Your Children

CANCER IS NOT an easy subject to talk about. Sometimes this means that parents try to avoid the topic for fear that they will scare their children or in order to “protect” them. The problem with this approach is that children are observant, bright and tuned in to what is happening around them, no matter what age they are. Children are aware of hushed conversations that take place around them, and they are quite skilled at picking up on the seriousness of what is happening just by watching the actions of people around them. Without having the proper information, children tend to imagine the worst. So, when Mommy is diagnosed with cancer and it’s not talked about, your child’s fear, sadness and anxiety will likely only increase.

By focusing on the opportunity to share, support and work together as a family, you can grow stronger and closer.

Telling Your Children
Experts know that children have a smoother adjustment and are less anxious when they are aware of what is happening during your surgery and treatment and feel included. By talking to your children about your breast cancer as soon as possible, you are able to establish a family environment of safe, open communication. This openness will allow you to share what you want to share about your cancer, your treatment experiences and the effects this may have on you and your family. You will also be able to clarify and correct any misinformation your children have or may have overheard about cancer and serious illness. Let your children know, to the best of your knowledge, what will happen next in your treatment. It is also helpful to talk to them about how their daily routine might change or be affected. Focus on the upcoming days and weeks, and provide information about long-term plans if or when children have a specific question, concern or strong desire to know more.

If you or your family desire privacy about your diagnosis, it is appropriate to let children know that there are a number of special people they can talk to about it whenever they want – and list these people for them. Then you can explain that this is something you would like to keep private for now. For many children, talking to their friends, classmates and people in their community is a way to process everything that happens in their lives. If you desire privacy, you must ensure that there are special people clearly identified whom your children can talk to about their feelings and thoughts and who can answer any questions they may have.

**Using Simple Language**

**Remember to use** simple language, giving a little bit of information at a time, and use the same terms consistently when explaining what illness Mommy has, what will be happening to Mommy and why Mommy is in the hospital. If your family has a special word for cancer, make sure that all caregivers are aware of it and use that specific word when talking to your children about what is happening. Keep the explanations simple and try to avoid over-explaining. Concrete explanations also help – such as “good cells, bad cells” or “healthy cells, sick/cancer cells.” Giving information in small bits over time also allows children to process each piece and helps them avoid feeling overwhelmed.

Try not to use medical terms or language that children are unfamiliar with. Often such terminology sounds scary or has more than one meaning. Start simple, and as children gain awareness about cancer, cancer treatment and medicine, you can clarify the different terms associated with each word or procedure.

**Here are some simple medical terms explained in child-friendly language.**

- **I.V. or intravenous** – “A special tube that puts medicine or water into Mommy.”
- **CBC blood test** – “Blood has three special parts in it: White blood cells protect you from germs, red blood cells work hard to carry oxygen to your whole body, and platelets help you to stop bleeding and make a scab when you get a cut. All those parts float around in something called plasma. A complete blood count (CBC) test is a way for doctors and nurses to look at and count each of these parts.”
- **Chemotherapy** – “Medicine that is specially mixed to help make Mommy well. Sometimes this medicine comes in a pill and other times it is a liquid that goes through a special tube (I.V.) into Mommy.”
- **Radiation** – “A special way of destroying cancer cells by using powerful invisible (X-) rays.”
- **Biopsy** – “A special way that doctors can check what is wrong inside Mommy’s body. This will help the doctor to figure out the best way to make Mommy feel better.”
- **Surgery or incision to remove tumour** – “The doctor will make an opening in Mommy’s body to remove the cancer/sick cells/sick part.”
- **Mastectomy** – “The doctor will remove or take off Mommy’s sick breast(s) where the cancer is.”
Answering the “Why” Questions

“WHY DID THIS happen?” is a common question children ask after being informed of Mommy’s diagnosis. Children’s basic understanding about illness is that something causes an illness to happen, such as a cold, which is contagious and can be shared.

**A FEW IMPORTANT POINTS SHOULD BE CLARIFIED FROM THE BEGINNING, SUCH AS:**

- “Nothing you said or did caused Mommy to get sick.”
- “Mommy is not sick because you did anything bad or wrong.”
- “Cancer is not something that you can catch from Mommy like a cold. Mommy cannot give this sickness to anyone.”
- “We do not know why Mommy got sick. Even the doctors may not be able to answer that question.”

Questions about Death

**IF YOUR CHILDREN** ask whether cancer could cause you to die, you must be ready with a response that you feel comfortable with. From a very early age, children may associate a cancer diagnosis with the threat of dying. Parents may underestimate their child’s need for information and try to protect them by choosing to avoid discussing emotionally charged topics. Avoiding questions about death and not talking about this connection does not protect children from potential anxiety and fears. Talking about death may feel uncomfortable or strange but is necessary to ensure that your child understands what death is and how your illness will affect your life and theirs.

Faced with the news of Mommy’s cancer, many children will wonder: “Will you die?” They may ask you immediately or wait many months after the initial diagnosis before asking. The response and the information you give will be shaped both by your personal feelings and beliefs about death and dying, as well as your child’s age or developmental level of understanding. You will need to be able to articulate your own beliefs about death, and your children will need the topic to be open for discussion so they can ask questions freely without feeling embarrassed, guilty or fearful.

**HERE ARE SOME HELPFUL RESPONSES TO QUESTIONS ABOUT DEATH:**

- “Some people do die from having cancer, but a lot of people also get better and live to be old.”
- “The doctors and nurses are doing everything they can to help Mommy get better. The doctor thinks that Mommy will be fine. Lots of people who get the kind of cancer that Mommy has live for a long time. I will tell you if anything changes.”
- “Right now the doctors say that Mommy is doing fine, the medicine is working and making Mommy better. If anything changes I will tell you.”

Always use the word “die” and/or “death” when discussing and explaining death and dying to your children. Gentle substitute words, metaphors and phrases may seem nicer and easier to say, but they can cause a great deal
of confusion and upset. For example, referring to death as a deep sleep can cause children to fear sleep or be afraid that Mommy has died when she is merely sleeping. Tell your children what you expect to happen in the next few weeks and/or months so that they do not think that death could happen at any moment. Let them know that it is normal to cry, be grumpy or feel fearful when people around them are sad and worried.

It is also important to remember that children may have a distorted sense of what “death” actually means, since many cartoons and movies include story lines where characters come back from death and news and television programs often portray death as something violent. So be sure to talk about the differences between real death and TV/movie deaths.

Finding natural examples of death and the life cycle in nature can help children understand death as a natural part of the life cycle. Look outside or around your house for examples of death. This may include a dead flower, insect, bird or squirrel. Point it out and explain to your children that the flower/insect/bird/squirrel is dead, and that means they are no longer alive. They cannot move, eat, breathe or grow anymore. They are dead.

Seek professional assistance if you need support or assistance from a doctor or medical team member when speaking to your children about death.

Repeat Repeat Repeat

“Are we there yet?”

Young children often ask questions repeatedly, not to drive you crazy but because they need to continually check in and clarify for themselves what is happening and why. This is perfectly normal, so be prepared and tolerant. Stay consistent with your responses, using the familiar family terms.

It is important to check in with your children every now and then, asking them if they have any questions about what is happening. Remind them that if they hear different things about cancer from their friends or on TV they should discuss this with you so you can clarify it. Young children are often magical thinkers, so clarification about cancer and cancer treatment needs to be an ongoing and continued routine. Children gather a great deal of misinformation from their friends, TV and the Internet, so check in regularly to correct misunderstandings and misinformation.

Start talking to your children early on in your diagnosis. Initiate conversation with them and incorporate a number of different media to enhance your discussion, such as books, simple pictures and videos when appropriate. Create an open environment for children to ask questions.

If your child asks you something and you are unsure of or don’t know the answer, it is perfectly ok to say:

“That’s an important question, but I’m not sure of the answer/I don’t know the answer so I can’t explain it right now. Let’s talk later once I have a chance to talk to my doctor/nurse about it.” Make sure to follow up with your child about their question once you know the answer.

It is also helpful to look for opportunities when “teachable moments” present themselves to talk with your children about their thoughts, feelings, worries and questions. For example, these moments may come while watching a movie where a character gets sick and dies. Your child may have questions about the illness and why the person died and what happens to that person after they die. Other teachable moments may present themselves when you are walking down the street – you may see a person smoking and your child asks why someone would smoke if they could get cancer from it. Or, you may see a dead animal in the park and your child asks if they had cancer and died. All of these scenarios are great opportunities to clarify everything and outline your beliefs about illness, cancer and death with your child.

Promoting and Supporting Children’s Coping

Keep routines as normal as possible and limit the number of different caregivers spending time with your children. This will help your children feel confident that their needs are being met. Young children often react to the changes around them, not to the actual illness, because they don’t understand the impact or meaning. Both younger and older children feel safer within their regular routine, so try to keep things familiar and consistent.

Some children may have a difficult time separating from you for your numerous appointments at the hospital. A transitional item can often help. This could be a toy or stuffed animal that is identified as a “Mommy
loves you” doll or bear. It is for hugging when your child wants a hug from Mommy but you are in the hospital. Older children may like to pick a special T-shirt of Mom’s to snuggle or wear at bedtime while Mom is in the hospital. Other children may prefer to keep a photo of Mommy in their school bag or bedroom. All of these items can help a child cope and manage better through periods of separation.

Children are constantly watching and taking their cues for how to respond to any given situation, such as a diagnosis, directly from their parent’s actions, reactions and responses. If a parent is demonstrating anxiety and upset, children will often respond with anxiety and upset, too. Seek out the support you need to help you reduce your own stress about your diagnosis and treatment, and take the necessary steps to ensure that you find appropriate supports for your coping and stress-reduction needs. Some helpful stress- and anxiety-reducing strategies are deep breathing, yoga, meditation, exercise, dancing, listening to music, participating in a favourite hobby or activity and talking to a counselor or therapist; in some cases, medication may be necessary to assist you with stress and anxiety.

Remember that all moments spent with your children are meaningful and fulfilling in some way.

It is also important to understand that treatment for breast cancer can be hard on your body and the side effects can be quite significant. It can be difficult to take care of yourself, let alone find the time and energy to care for your children. This can cause feelings of worry and guilt about your role as a mother. Remember that all moments spent with your children are meaningful and fulfilling in some way. It is all right if all you can do some days is let your child spend time sitting with you for a few minutes. It is essential that you ask for help from friends or family when you feel you need it.

Listening to Your Children

With so much going on during cancer treatment, and in life in general, we are often too busy to really listen to our children. While that’s understandable, it’s important to find time to give children our undivided attention. Listening carefully to your children builds their self-esteem by letting them know that they’re important to you and that what they are saying and how they are feeling is equally important. Just listening can lead to valuable discussions about a wide variety of sensitive issues.

Listening carefully also helps you better understand what your children really want to know as well as what they already understand. Listening can help you avoid talking above a child’s level of understanding and possibly confusing them. Remember to repeat and revisit past explanations and correct any misunderstanding or misinformation your children may have. For example, if your child asks, “What is chemotherapy?” the week after you’ve talked with him about this, before you answer, ask him what he thinks it is and what he remembers from your talk. If he says, “I think it’s something you eat that makes you act funny,” then you have a sense of his level of understanding and can adjust your explanations to fit.
Listening to your children and taking their feelings into account also helps you understand when they’ve had enough. Suppose you’re answering your child’s questions about surgery. If, after a while, your child says, “I want to go out and play,” stop the talk and reintroduce the subject at another time.

Managing Comments from Others

No matter how comfortable you and your children are talking about your breast cancer diagnosis and treatment, there may be people in your life who react and respond differently to the news about your diagnosis. Some of these responses may be negative, so it is important to prepare yourself and your children to handle these situations in a way you feel comfortable with.

Although you and your family may be approaching your treatment as a positive means to make you better, it is not uncommon for people in your social circle, and sometimes even strangers, to comment aloud about their personal thoughts, fears and stories about cancer. This may happen in front of your children, and when the comments are negative or sad, this can sometimes cause distress in children. Teachers, neighbours and friends do mean well when they respond to the news of a cancer diagnosis as sad news, so it is important to prepare yourself and your children for how to respond in a positive way to these sad comments.

As a family, prepare some scripted responses that you feel comfortable with that simply state the facts you wish to share. Some examples are:

- After hearing a child’s teacher say, “Oh, I’m so sorry to hear about your Mommy’s cancer. That’s so sad.” Your child can say: “Yes, we all felt sad when Mommy found out that she had breast cancer, but Mom and her doctors are working hard to get rid of this cancer.”
- A neighbour shares, “Oh, my aunt died after battling breast cancer for four years.” You and/or your child can say: “Some people do die from having cancer, but a lot of people also get better and live to be old.” Or, “The doctors and nurses are doing everything they can to help Mommy get better. The doctor thinks that Mommy will be fine. Lots of people who get the cancer that Mommy has live for a long time.”

Cancer and the Media

Much of the time when children hear and see news about cancer in mainstream media (such as television, newspapers and magazines), it is when someone has died or when funds are being raised to support cancer research in someone’s memory. This can be especially hard for children when they are trying to focus on the positive outcomes of your cancer treatment.

The same statements and scripted responses provided in earlier sections of this booklet can be restated to remind your children that not everyone who has cancer dies. It may be helpful to give some examples of people who have had cancer, completed treatment and are now happily living their lives.

Hospital Visits: Inpatient and Outpatient

If a child is able to visit Mommy in the hospital, it is important to explain that there might be special medicine in a bag/tube (called an IV) that is helping Mommy feel better, or special bandages/Band-Aids or drainage tubes where Mommy has a “boo boo” or has recently had surgery. It is also a good idea to talk about whether or not lying in bed for a snuggle with Mommy is physically possible during the visit, which often depends on pain level and post-surgery or treatment areas that may still be healing.

Many young children are quite comfortable in the hospital and want to play with Mommy just like they do at home. Others are fascinated with
the hospital environment and equipment and may not pay full attention to Mommy during the visit; this is normal as children take in all the new and different materials, people and smells in the hospital. Older children are more aware of what takes place in a hospital and may have more questions or concerns for and about Mom when visiting. Hospitals often encourage short tours of certain clinic areas for children of patients to familiarize them with the treatment environment.

Some children, regardless of preparation, may not want to visit Mommy in the hospital. Open communication and discussion is important at this time to determine if the child needs more information about what is happening or additional support and preparation from a professional child life specialist or social worker. With some support and preparation, all children can have a positive and successful visit with Mommy in the hospital. But try not to force a child to go to the hospital when they express a desire not to go. Continue to provide information and invitations to visit and encourage them to create art, poems or crafts for Mommy and speak to her regularly over the phone.

If you are not comfortable having your child visit you in the hospital, ask your partner or a family member to suggest that they draw a special picture for you or go for a walk and pick a flower for you. If the child is older, encourage them to write a special letter or poem.

Attending outpatient hospital appointments with Mommy can be much more relaxed and far less stressful than inpatient visits. Some appointments or visits may be long, so be sure to bring appropriate games, toys and materials for you and your child to play with while waiting. Small snacks and drinks might be needed to get through longer wait times, so pack and plan accordingly. Having a fun picnic together in the waiting room or treatment room can be a positive hospital experience for everyone.

**Reactions to Changes**

**Hair Loss**

*EVERY PARENT IS different and every child is different, so naturally there are different reactions from both parents and children to hair loss and other changes in appearance due to cancer treatment.*

Explaining potential changes in appearance before treatment starts gives your children a chance to ask questions and process possible outcomes. Children need to know that some of the treatment side effects may make it appear that you are getting sicker. Keeping them informed and being straight up about side effects is important.

**HERE ARE SOME SIMPLE EXPLANATIONS ABOUT HAIR LOSS:**

- “The medicine Mommy needs to take to help me get better is very strong. My hair may fall out but it will grow back after I finish treatment."
- “I may look different on the outside now, but on the inside I am still the same Mommy. I still love you just as much as I always have.”
- “My hair has fallen out because of the medicine I need to take. You may see Mommy wearing different hats, scarves or special hair called a wig to cover my head while my hair is gone.”

Children react in many different ways when hair loss occurs following chemotherapy. Some express feelings of worry, while others may be initially scared or embarrassed by the physical change. Other children find their mother’s hair loss quite funny and may joke about it. Some children report that they do not really care about the hair loss at all, they just want their Mom to get the treatment that will help her get better. All of these responses are normal.

Some children may express a desire that Mom wear a wig or hat when she picks them up at school or when their friends come over. Although Mom may feel quite confident and positive about her hair loss, even choosing to shave off her hair before chemo begins, some children may want time to adapt to the change in appearance before “going public” with Mom’s hair loss to their peers. Some people may not want to see anyone when their hair falls out and would rather remain private during the chemotherapy stage. Talk openly to your children about how they feel and how you feel about your hair loss.

**Changes in appearance due to surgery**

*FOR ALL BREAST cancer surgeries, the goal is removal of the cancer.* This is the information that is most important for your children, at any age. Once you have communicated the goal and reason for the mastectomy...
or lumpectomy, you can move on to what that specific surgery entails — removal of part of or the entire breast(s). Use the body terms your family has always used for breasts when you discuss this with your children, but let them know that doctors and nurses call them breasts.

“Mommy is going to have surgery/an operation to take out the cancer/bad/sick part/cells. When the doctor does this, it is going to change how Mommy looks here [point to breast(s)].”

**LUMPECTOMY:**
“After Mommy’s operation/surgery I will look a little different. There may be a scar from the opening that was made to take out the cancer. This scar will heal and get better over time.”

**MASTECTOMY:**
“After Mommy’s operation/surgery I will look different. To take away the cancer/sick part, the doctor has to remove Mommy’s breast(s). There will be a scar on Mommy’s chest area when my breasts are gone. This scar will heal and get better over time.”

**RECONSTRUCTION:**
If you choose to have reconstruction, the timing of your reconstruction (immediate or delayed) will determine what and how you tell your children. Also, the reconstruction method you and your doctor choose for you may be explained differently.

- **For reconstruction immediately following the mastectomy, you can say:** “After the doctor takes away the cancer/sick part, he/she will be building a new breast for me. This means that other parts of my body will be sore after the surgery/operation, not just my chest. After the surgery I will have to sleep over at the hospital. After the surgery I will have breast(s).”

- **For reconstruction long after a mastectomy, you can say:** “My doctor is going to make a new breast(s) for me. To do this, he/she needs to do another operation for Mommy. That means I will be going back to the hospital for the operation and a sleepover. This operation is not to remove any cancer/sick cells. This operation is to create new breast(s) for Mommy. After the surgery I will have breast(s).”

**Changes in activity level**

**Children need to** be told that Mommy may not have as much energy as usual or be able to do all the regular things she does because the medicine and treatment can make her tired and/or cause her some pain or discomfort. Start by explaining that these are normal side effects and Mommy won’t always feel this way but that it will take some time to feel better.

**Here are some helpful statements for kids:**

- “I would really like to do the things we usually do together, but right now I can’t/don’t have the energy to do so. Let’s think of some activities we can do together while you sit with me in bed.”

- “The medicine Mommy is taking is very strong. The medicine helps me get better, but while it does that it also makes me feel tired/sore/sick.”
When you are feeling tired, sick or in pain, try to offer quiet and gentle opportunities to spend time together as a family. Some fun ideas include a family movie night at home, complete with a favorite classic film and popcorn or a special treat. Enlist your children in making tickets for the movie and pretend money for the concessions, and pretend you are really at the movies. Remember to turn the lights out and sit together! Other ideas could be sharing story time or having a family board game night. All of these activities can be adapted to the bedside if you need to stay in bed.

Financial changes

Children often overhear adult conversations, both intentionally and unintentionally. After a breast cancer diagnosis, the occurrence of this may increase due to the many issues that parents, friends and family members need to discuss in relation to the treatment schedule and how to manage all aspects of family life during the “new normal” period.

Oftentimes following a breast cancer diagnosis, moms may take time off work. This time off can cause some school-age children to become concerned about the family finances and whether the family will be negatively impacted by this loss of income while Mom is undergoing treatment.

“How will we pay the bills? Who is going to buy the groceries?”

It is important that you explain any time off work in an age-appropriate way to your children. Letting your children know that, no matter what, their immediate care needs (food, shelter, clothes, etc.) will always be taken care of is important. For older children you may choose to elaborate and give them more details about how your time off work will be supported through sick leave or employee benefits.

Remember to seek out assistance if you are in need of additional financial supports during your breast cancer treatment.

Discipline and Behaviour

BAD DAYS JUST happen sometimes. Everyone has them, even children. Although your children may need you to go a little lighter on them at times now, they actually need the boundaries and structure that your normal family rules and expectations provide. However, it is important to recognize that distress or upset can come out in many different ways through behaviour. Be patient and try not to expect your children to behave or act more maturely than they behaved before your diagnosis – even though you wish they would.

All children want attention, whether it is negative or positive, from the adults around them. When family illness interrupts the normal focus on them and their needs, children may act out to ensure that attention is paid to them. If behaving badly is getting them attention, children will continue to behave badly because it is working for them. If parents are unable to create some daily one-on-one time with the child, have a family member or designated caregiver temporarily take over a one-on-one routine, such as bath or story time, to ensure that the child gets some special attention. Continue with normal family behaviour.
management strategies and rules. It is important that children are given consistent messages about acceptable and unacceptable behaviour.

As much as you can, give your children extra time and support. Try to find moments to have fun, whenever possible. Tell jokes over dinner together. Be spontaneous. Take an unplanned trip to the movies. These moments together can help restore a sense of normalcy for you and your family.

After Treatment:

“When will things go back to normal?”

This is a common question that can be really difficult to answer. A breast cancer diagnosis changes your life. Remember, this is the new normal and returning to your (and your family’s) daily routine may take time. The daily routine may also experience permanent changes even after you have finished active treatment. Children often expect that when something is “finished” everything goes back to the way it was before – including Mom.

The actual way you feel physically might be different than how you felt before your diagnosis and treatment. With treatment, some Moms experience weight loss while others gain weight. Even after treatment, energy levels can remain low, so expect that it will take some time to heal and figure out your new routine. It is important to note that how doctors treat breast cancer is unique to each person, so some Moms can even have an overabundance of energy – this is different for every individual.

TO EXPLAIN THIS TO YOUNG CHILDREN, YOU SHOULD RELATE IT TO SOMETHING THEY HAVE EXPERIENCED:

“Remember when you were sick with the flu? It took time after you were sick to feel well enough to eat and go back to school/daycare. Mommy needs time to feel well enough to do all the things I need and want to do, too. It takes time.”

Recurrence:

The “What if’s?” can be particularly scary for children, because there is no way of predicting or knowing if a recurrence will happen to a woman after successful cancer treatment and remission. If the doctors are concerned about a recurrence, it is essential that you let the children know this ahead of time, and explain that you will be closely monitored by your doctors to ensure that if you experience a recurrence new treatments will be started as soon as necessary. It is really important to tell children about the possibility of a recurrence. If they expect it to never come back and it does, it can be very upsetting, even more so than when Mom was initially diagnosed.

Children need information about any possibilities for additional treatment, future surgeries and different cancers or illnesses that could affect Mom. This information is important to help children feel prepared and so they will understand future plans, appointments and any changes that may take place.

If you have had a recurrence and begin talking to your children about it, you will be sharing information with them and showing them through your feelings and actions how they too may react to the news. Sharing feelings and talking about the reasons why you are having these feelings helps children to learn appropriate and very normal responses to the news.
All children are individuals, growing and developing at their own natural pace. When considering developmental milestones, behaviours and specific skills that children naturally acquire as they grow, it is important to remember that each child reaches these in his or her own time.

Ages and Stages

Infants: 0 to 12 months

THE WORLD IN WHICH AN INFANT FUNCTIONS IS MOSTLY BASED ON THEIR IMMEDIATE SENSORY EXPERIENCE:

- **Touch** and how physical contact feels to them and their body
- **Smells**, both familiar and unfamiliar
- **Taste**, familiar and unfamiliar
- **Sounds**, including volume, frequency and familiarity
- **Sight**, what and who they see in their immediate surroundings

THE SENSORY-BASED WORLD of an infant can be affected by Mommy’s illness in all of these areas.

Touch and physical contact with Mommy may change following treatment or surgery, and the familiar way an infant was fed, at the breast or close to the chest, may change due to a mastectomy, lumpectomy, reconstruction, pain or skin irritation. To offset this change in touch, all caregivers need to offer extra physical contact to the infant in a variety of ways. Mommy can snuggle her baby higher up on the chest, closer to her neck and face, which is a nice way to give skin-to-skin contact while avoiding the breast area. Infant massage and positive touch is another alternative, offering physical closeness and contact without Mommy having to hold the baby near her torso and surgical sites.

Mommy may smell different following surgery, treatment or a trip to the hospital. Similarly, the other parent and caregivers may smell different after spending time in the hospital with Mommy. Infants will be able to smell this difference. Some may respond to Mommy or other caregivers by pushing away initially or fussing. This is normal and will most likely happen until the infant can smell the distinct smell of the individual under the new unfamiliar smell of the hospital. Don’t take this personally. Just
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be patient and give the baby some time to figure out that it is indeed you.

Switching an infant from breast milk to formula after a breast cancer diagnosis is a common occurrence. The taste of the formula and the bottle nipple may take the infant some time to get used to. A baby may refuse the formula and bottle at first. Be patient and make sure that the type of formula and nipple used is consistent. The infant will eventually assimilate to the new tastes.

New sounds that a baby may hear in the hospital while Mommy is an inpatient or outpatient will be unfamiliar to them and can cause many different reactions. Some infants will enjoy the constant hum of activity, machines and people at the hospital, while others may be upset by the noise. For some infants, the noise of the hospital will lull them to sleep; others may be more difficult to settle and may have trouble falling asleep at the hospital. Both of these responses are normal. Over time the sounds of the hospital will become more familiar.

Infants will be introduced to many new people over the course of their Mommy’s diagnosis, treatment and recovery. They will also visit unfamiliar places, such as hospitals, doctors’ offices and other caregivers’ homes. Seeing all these new people and places can be overwhelming and upsetting for infants. Try to stick to a small number of consistent caregivers and places the baby visits. This will help maintain a familiar routine that is comforting to infants. If you must bring your baby to all your appointments, be ready with lots of positive support and extra-loving interactions. Bring along a few familiar items from home to ease the baby’s transition into a new place.

Infants are not old enough to understand illness and the impact of the illness and treatment on Mommy’s life, but they are able to understand the effect it will have on their life. A baby’s main concern is disruption in their daily routine and changes to relationships with primary caregivers, which can be quite disturbing for them. Try to keep the daily routine as consistent as possible and reduce the number of additional caregivers.

Babies will let you know if they are feeling affected by Mommy’s illness with changes in their eating or sleeping habits or by acting extra fussy or clingy. These are all likely signs that they are feeling insecure or confused about what is happening in their world. What infants need most at this time is comfort, positive physical contact and a good daily routine. Give your baby extra physical contact and do not worry about spoiling them at this early age.

**Toddlers: 1 year to 2.5 years**

Toddlers, like infants, are unable to understand explanations about Mommy’s illness and how Mommy’s illness will affect Mommy. They are only concerned with how Mommy’s illness, treatment and recovery will affect their life. Toddlers are totally focused on themselves and live in the present, so they are unable to understand time concepts beyond major daily routines such as meal time and sleep time.

**WHEN TALKING TO YOUR TODDLER ABOUT YOUR CANCER, USE REPETITION AND THE SIMPLEST LANGUAGE POSSIBLE:**

- “Mommy is sick.”
- “Mommy has a boo boo here/is sick here [point to breast (s)].”
- “Mommy is going to the doctor.”

Whenever possible, model gentle touches to your toddler to demonstrate how they should appropriately touch and interact with Mommy so that surgical and/or treatment sites are not injured by a well-meaning rough hug. Gently stroke your toddler on the hand, shoulder or chest and say “gentle” aloud while you do this. Then take your toddler’s hand in yours and stroke your own body gently with their hand and say “gentle” aloud. Toddlers enjoy mimicking and will love to go back and forth taking turns doing gentle touch.

Separation from a caregiver can be especially upsetting because toddlers do not clearly grasp that someone will return if they have left for a short
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while. They can understand the concept “all gone” but not that someone or something will be back soon. Toddlers may ask repeatedly, “Where’s Mommy?” so it is important to tell them that Mommy is at the hospital or doctor’s office or lying down right now, every time they ask. This distress can be offset with lots of affection, consistent caregivers and a predictable calm routine.

Again, like infants, toddlers may react to these new changes in Mommy and disruptions to the daily routine with different eating and sleeping habits or by acting fussy and clingy. In addition, toddlers may experience some regression, which means that they may be unable or unwilling to do things that they previously were able to do. Some examples are bedwetting and using a bottle again instead of a cup. This is a normal response that indicates that they are feeling insecure about their world. Accept this need to regress. It is a toddler’s way of returning to an age of safety and familiarity. It will be temporary, so scolding and punishment will not be effective in making this behaviour stop. What toddlers need most at this time is comfort, familiar people and places, and a good routine.

Some toddlers are completely unconcerned with physical changes, while others can be upset when Mommy’s appearance changes and it may take some time before a toddler feels comfortable if Mommy looks different. This may mean that a toddler cries when they see Mommy or won’t go to her. Try not to take this personally. A toddler needs to see Mommy acting like “Mommy” despite the difference in appearance before they are comfortable enough to go to her.

Preschoolers: 2.5 to 4 years

A preschooler’s world has opened up to include not just them but also their parents and immediate family members. They still cannot understand complex explanations but they have a limited understanding of time in the most basic forms, such as, yesterday, today and tomorrow. A preschooler is beginning to form ideas and connections about how the body works and has a limited understanding of the concept of illness. Most preschoolers understand being sick as having a cold, flu or something contagious like chicken pox.

When explaining Mommy’s cancer to a preschooler, keep the language simple, use your normal speaking voice (please, no whispering – it implies secrets), be brief and allow for play breaks:

• "Mommy is sick. It is not like a cold."
• "The sickness is called cancer."
• "The doctors are helping Mommy get better."
• "The doctors are giving Mommy special medicine."

A preschooler may show intermittent sadness, fear, anger and happiness all in short succession. This is normal, as they are reacting to the changes in their routine.

Preschool-age children are visual learners, so when giving them simple explanations about Mommy’s cancer, it is helpful to use dolls or puppets to help demonstrate what is happening to Mommy’s body (lump and surgery) and what will happen over the course of treatment (scars, healing and medicine through a PICC line, port or IV). Having the preschooler place a Band-Aid on the treatment area will help them concretely understand that this is the area where Mommy is sick and the doctors are working hard to fix it. Remember to keep these explanations simple and short – do not go beyond the child’s attention span or developmental level of understanding. Many preschoolers need to digest small amounts of information at a time, with play in between discussions, since play is a natural way that children work through and process new information. When your child seems distracted, that is a signal to stop the discussion and continue it at a later time.

Preschool children react to feelings more than facts, so know that your preschooler is watching and reading your body language for signs...
about how to react to the news that Mommy is sick. This can mean that if someone in the family is crying, they too will cry. Different feelings and emotions are still new to a preschooler and can be hard for them to control. A preschooler may show intermittent sadness, fear, anger and happiness all in short succession. This is normal, as they are reacting to the changes in their routine, their frequent separations from Mommy (or both parents as the hospital appointments increase), additional caregivers and the shift of attention of friends and family from them to Mommy.

Encouraging physical activity is a good way to promote the release of feelings and offering expressive arts activities, such as drawing, painting and music, also helps preschoolers express their emotions.

School-age children: 5 to 8 years

School-age children are starting to explore the world around them more but are still mainly focused on their parents, their immediate family and the familiar routines in their family. At this age, children still remain very dependent on their parents and are now more concerned with their safety and the safety of their family as they are starting to think logically and can differentiate between simple and serious illnesses.

When disclosing Mom’s illness to a school-age child, present clear information about what is happening:

- “Mommy has cancer.”
- “Cancer is a disease, which is different from a cold.”
- “Nothing you did caused this to happen.”
- “You cannot catch the cancer from Mommy.”
- “No matter how many appointments Mommy will have, you will be taken care of by __ (parent/family member/caregiver).”

When explaining what will happen to Mommy during treatment, use phrases such as:

- “The doctors will make an opening to take the cancer out.”
- “Mommy will have a special bandage where the doctors made the opening.”
- “Mommy will receive medicine through a special tube that goes into her body.”

If you are comfortable showing the PICC line, port, I.V. or Hickman line to your child, it is important to explain that it is there to get the medicine into Mommy’s body to help make the sickness go away. School-age children are fascinated by how the body works and by equipment and machines, so whenever possible explain what the different parts of treatment do and what effect they may have on Mommy. When visiting the hospital, take time to explain what each piece of machinery does or ask the medical team to help you explain this to your child.

Give a school-age child plenty of opportunities to talk about Mommy’s illness, share their feelings and ask questions. Some school-age children just want to “be together.” Try to avoid forcing discussions about Mommy’s illness on them. Check in regularly and ask them how they are feeling or if they have any questions. It is good to regularly explore...
your child’s understanding of what is happening by asking them to tell
about it.

With school-age children, great importance is placed on being the
“same” as their friends and peer group. This means that they may try hard
to appear the same as usual in public, choosing to only show their concerns
and emotions privately, and they may want to continue as normal with
outside activities. School-age children may seem most concerned with how
Mommy’s illness will impact them – a different caregiver may be picking
them up from school or sports, they worry about whether they will be able
to continue attending a sport or extracurricular activity, and they may also
worry about their friends’ questions and reactions to Mommy’s illness and
how to respond to them. Practice scripted responses to common questions
or comments your child’s peers may have about Mommy’s cancer. This
helps your child gain confidence and can reduce feelings of embarrassment.

School-age children: 8 to 12 years

This older school-age group tends to share many of the same
communication needs as the earlier group, but developmentally, older school-age
children are starting to move outside and away from the family to develop
more peer relationships.

When discussing Mom’s illness, try to be specific and provide clear
information about the diagnosis and treatment. Give enough information
in the form of facts to allow the child to think logically about what is hap-
pening to Mom. Most older school-age children are aware of cancer and
that there are different types of cancer but still lack full understanding of
the symptoms and disease process. They may have questions about the
medical team’s ability to care for you, so allowing them a chance to ask
questions openly is important.

This developmental stage experienced by older school-age children
shifts their focus from family to friends, so the impact of Mom’s illness
is considered more in terms of how it affects the child socially. This
sometimes presents itself as concern about how Mom’s illness has
interrupted their life, instead of concern for Mom. This is a normal part
of development, so be patient and understanding. At this age and
developmental stage a child may seem selfish about how Mom’s illness
is affecting them, but this is how they look at the world as a whole.
However, some older school-age children can assume overly grown-up
roles and responsibilities and may try to take on a “caregiving” role
with Mom and the rest of the family. Allow them to assist with your
care through appropriate tasks such as bringing you extra pillows
or blankets or helping prepare a snack for you. Giving extra tasks
or asking for help with certain jobs around the house is fine, but try
not to overload them. Keep their tasks focused on those that apply to
them directly – like making their own lunches or keeping their room
clean. Encourage these children to continue seeing friends and to be
actively involved in sports and related peer groups.

This developmental stage experienced
by older school-age children shifts
their focus from family to friends,
so the impact of Mom’s illness is
considered more in terms of how it
affects the child socially.

As older school-age children explore their feelings and how their feel-
ings impact others, their immediate feelings are commonly kept private.
This is because they are just learning how feelings are communicated
outwardly to others and are now able to recognize how others feel. Due to
this learning process, anger can be an easy “go to” emotion, before sadness
or worry can be appropriately articulated. These feelings may be directed
at family members because older school-age children are often closest to
their immediate family and may feel safest exposing these intimate feelings
to family. By sharing your own concerns, fears and feelings about your
illness, you can assist these children in helping them sort out their mixed
emotions. This, in turn, will normalize the range of feelings your children
may be experiencing.
Teenagers: 13 onwards

Being a teenager can be tough. Each teen is distinctly different and will experience Mom’s cancer differently. Teens want independence and are working toward it, but in many ways they still need their parents. At this stage of development, independence and increased time with peers is considered very important and is one of the biggest developmental milestones for this age. In fact, in the eyes of a teenager, friends are as important as family. As a result of Mom’s diagnosis, instead of doing what comes naturally to a teen and moving away from the family more and more, they are instead pulled back into the family as a part of the support network. This “push-pull” feeling can be difficult for a teen to adjust to, so try not to take it personally, be patient and give them time to figure out how this is going to work for them.

While teenagers have the cognitive ability to understand complex information about illness, they are still struggling with abstract concepts like the meaning of life and death. Teens may have misconceptions or misunderstandings about cancer and cancer treatment due to information they have heard from peers or through media and the Internet. Teens can be highly sensitive to deception and dishonesty, so give them lots of information about your illness and keep them informed about your health and treatment plans. Whether or not they appear to care about or want this information, it is important that you are open and honest and keep them up to date on what is happening. You can also offer them books, pamphlets and reputable medical websites if they want more information and encourage them to ask questions if they have any. Many teens need time to think about the impact Mom’s cancer will have on their life and may want to talk to someone other than a parent about it. Make sure you have other trusted adults available for open communication, such as an aunt or uncle, family friend, teacher or coach who is aware of the situation and comfortable participating as a support person.

Teenagers are able to share their feelings verbally but can also respond physically to these feelings due to normal hormonal changes. This means that strange or different behaviour could present itself, often in the form of anger or great sadness. Sometimes your teen may seem quite mature and may want to take on additional caregiving roles, while other times they may seem to regress and act as if they are much younger. It is important to remember that your teenager is just that – a teenager. Try not to place too much expectation on them. It is their job to help out around the house, but it is not their job to manage all the care needs of their parent(s) and younger siblings. Reassure your teen that you are still the parent. Stay consistent with your expectations of them and how you negotiate limits and respond to problem behaviours.
Summary

Many women newly diagnosed with breast cancer experience “information overload” as they struggle not only to learn new medical jargon but also to educate themselves on what it all means for their particular diagnosis and treatment plan. Keeping up with all the hospital appointments and tests, tracking results and remembering what questions to ask your doctor can seem like a full-time job. Figuring out how to explain what is happening to your children can add to your stress and overload. We hope this booklet has shown you that simple, honest words can help both your child and you. Every family is different and every child is different too.

Educate: Be open and honest. Tell your children you are sick, call it breast cancer and explain the treatment plan as best you can as it unfolds. Children cope best when they are well informed, so keep them up to date.

Engage: Try to involve your children in what is happening so they feel included. Allowing children to attend some appointments at the clinic or hospital, tour the chemotherapy area or meet the medical team that’s working to make Mommy better are all excellent ways to engage them and allow them to participate in a positive way.

Inspire: Ongoing communication is important, so encourage your children to ask questions and talk about what and how they are feeling. Lead by example. Try not to hide your emotions about your cancer and be ready to talk about them and explain them to your children in an age-appropriate way.

Expand: Select a few special caregivers, friends or family members to help out consistently with the children’s normal routine. This provides children with stability, structure and security at a time when certain aspects of their lives are changing.

Support: Seek support for yourself and your needs, which will enable you to better support your children through your cancer experience.

About Rethink Breast Cancer

Rethink Breast Cancer is Canada’s leading breast cancer organization exclusively focused on the needs of young women. We burst onto the scene in 2001 with a desire to change the face of breast cancer — to show that breast cancer is not just an older woman’s disease; that young women get breast cancer, too. When it comes to young women and breast cancer, the numbers may be small but the needs are very real. At Rethink Breast Cancer, we get it. That’s why we’re working hard on our mission to continuously pioneer cutting-edge breast cancer education, support and research that speaks fearlessly to the unique needs of young women.

Further information and resources can be found in the Resources section of the Rethink Breast Cancer website at www.rethinkbreastcancer.com or call Rethink at 1-866-RETHINK (738-4465).

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