Helping Children Cope with Breast Cancer

For many mothers, one of the first reactions to being diagnosed with breast cancer is, "What about my kids?" There is no one right way to help children cope with breast cancer, because each child and family is different. But, there are some general guidelines that can help different families meet the unique needs of their children.

Communication

Talking about what is happening is extremely important, but not always easy. It is normal to want to protect children from bad news, but children of all ages tend to be good at picking up parents' distress, even when parents think they are hiding it well. Having a clear explanation about what is happening helps children understand that they are not to blame for parents' worries and prevents them from creating explanations for changes that are just plain wrong, and sometimes much worse than reality.

USING THE WORD "CANCER" - Many parents wonder whether they should mention the word "cancer" to children and worry that this will make children more upset than just saying, "Mommy is sick." A problem with using only general words like "sick" or "booboo on my breast" is that children hear these words applied to them when they have colds or scrapes. They can end up feeling confused when you don't recover as quickly as they do, and worry that getting "sick" will be just as hard for them the next time.

TELLING CHILDREN ABOUT YOUR DIAGNOSIS—The exact words you use to talk with your children will depend on their ages, but children of all ages can benefit from knowing the name of the illness (breast cancer), the type of treatment and how cancer will affect their own, day-to-day lives. Sometimes beginning a conversation with a description of what children may have noticed already can make it easier: "I think you know that I've had a few doctor's appointments lately...we just figured out that I'm sick with something called breast cancer. My doctors are going to give me special medicine called "chemotherapy" (or, "radiation") to help me get better. I will be going to the doctor's office at the hospital for my medicine every week, and on the days I go, Isabelle's mom will take care of you until I get home."

COMMON QUESTIONS—Giving children the "headlines" then letting their questions guide the rest of the conversation can prevent children from feeling flooded with information and details, and can give you a sense of their concerns. Children may ask, or just secretly wonder:

"WHAT IS CANCER?"

"Our bodies are made up of building blocks called "cells" that are always making more of themselves to keep our bodies healthy. Sometimes a group of cells makes far too many new cells, and all the extra cells form a lump called a tumor. I have a tumor in my breast, and the treatments are going to shrink the tumor and help make sure a new one doesn't grow."

"HOW DID YOU GET CANCER?"

"No one knows exactly why some people get cancer and others don't...do you have ideas about how I got it?" Children's answers can yield surprising information. Preschoolers and young school age children may believe that something they thought or did caused your cancer, for example, wishing something bad would happen to you during a tantrum, or hitting you so that you got a "lump." Older children are sometimes aware of a connection between stress and illness, and may worry that they indirectly caused the cancer by





adding stress to your life. Children can be reassured that absolutely nothing they did caused the cancer, but that there are things they can do to help you feel better, like telling you a joke or drawing a picture.

"CAN I CATCH CANCER?"

"No, cancer isn't contagious—you can't catch it from another person. It's more like a broken leg than a cold."

And school aged children and adolescents may ask the question that many parents dread most:

"ARE YOU GOING TO DIE?"

It is tempting to promise, "No, never!" right away, but it may be almost as reassuring, and more honest, to convey lots of hope and optimism, but also not to make promises you can't keep. You might talk about the positive aspects of the situation, the plan of action and a reassurance that if the situation changes, the child will be informed: "Will I die?

Well, it's true that people sometimes die from the kind of cancer I have, but my doctors tell me they can cure my cancer. It was caught really early, and now I'm taking medicine so I can be extra sure it's completely gone from my body. I'm planning to live a long, long time. If I hear anything different, I will talk to you about it." Or, "I have a tough kind of cancer to cure, but my doctors think I will live a long time...I'm going to do everything I can to get better so we can get back to doing all the things we enjoy together."

KEEPING LINES OF COMMUNICATION OPEN—Once you've told your children about your diagnosis and treatment plan, then what? Check in and keep talking over the next days and weeks. You may have needed to ask your doctors the same questions more than once before the information really sunk in, and your children may need to do the same. Their reactions will change as the news sinks in and your treatment begins, and routines at home begin to change. It helps to encourage children not to worry alone, and to talk about their concerns and feelings with a loving adult. Questions like, "Are you hearing too much or too little about my cancer?" and "Are there questions (or feelings) you have but don't want to share with me? Who else could you talk with?" might help start children talking.

Parents seem to have a hard time asking about their children's feelings, perhaps because it is so difficult to see our children feeling sad or scared. Some children believe that sharing their feelings will be too upsetting for their parents, and need to be reassured that talking with another trusted adult is ok, even if it's not a parent. The things that upset your children may surprise you, so asking about their feelings can help your family figure out how to work together to lower children's distress. For example, depending on their age, your children may feel frustrated that they can't have friends over since you're not feeling well, or feel like their house is not their own anymore because so many visitors are stopping by to offer support, or feel overwhelmed by being asked to "step up to the plate" and help out with housework or caring for younger siblings.

A question like, "What bothers you the most about my having cancer?" sends the message that it's ok for kids to share negative feelings. Your job then is to listen, accept the feelings ("Mmm, I can understand how you'd feel that way!") and see if you can together come up with some solutions ("Would it help if I checked with Josh's mom to see if you could go there once a week to play? Had my friends over mostly while you're in school? Took another look with you at your list of chores?") Even if there's no easy solution, listening, letting your child know the situation won't last forever and even wishing with her that things were different, can help: "I'm glad you told me how sad and angry you are that we won't be able to go on the vacation we'd planned this year...my treatments won't last forever,



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so we will definitely plan another vacation, but I wish I could magically speed up time so my treatments would be done in time for us to go!"

Family routines

Children thrive when life is mostly predictable, and part of what can be upsetting to them about a parent's cancer is the changes in their day-to-day routine. Some changes are unavoidable, of course, but now is the time to think about asking for help—from family, friends, teachers, neighbors—in keeping your children's routines as normal and predictable as possible. The kinds of routines that anchor preschool children's days include those at preschool drop-off and pick-up, naptime, mealtimes and bedtime, and for some children, routines around using the toilet. Giving clear, detailed instructions to new caregivers can help children feel more settled even when you aren't there: "Jenny has milk in the sippy cup with dinosaurs around 10:00, and then a nap with her blue blankie right after that. She likes to hear the Raffi tape as she goes to sleep."

School-aged children also enjoy regular mealtime and bedtime routines and benefit from staying involved in their usual activities, such as music, sports and clubs. Children in grade school often have a tremendous amount to organize, but lack the skills to consistently plan ahead, which can be a problem if you aren't feeling well enough to make last minute trips for supplies or forgotten books or homework. Letting a teacher know about your treatment, and that you'd appreciate early warning of any long-term projects, and being willing to ask the parent of a classmate to buy extra clay and pipe cleaners when they do their own child's shopping can help. If informed about your cancer, your child's teacher is in a good position to notice if your child is having any trouble with friends or schoolwork, and can then let you know before problems have a chance to grow.

Adolescents, though more independent and less often home, continue to need structure and support from parents. For example, family time that isn't focused only on cancer, regular mealtimes, and parents' continued interest in their lives are all helpful for teens. It is easy to assume that your teenagers will be able to do quite a bit around the house when you are not feeling well, but asking too much of them can make it difficult for them to stay involved in the friendships and activities that help them cope. It can help to let your adolescent know that you understand how important these things are to him or her, and to work together to negotiate some reasonable expectations.

Family time

Along with maintaining normal routines, it will help if your children can still enjoy time with you in which cancer isn't the main focus. It can be reassuring to everyone to feel that the good parts of life are going on, even in the face of illness. You may find that you have many visits and phone calls from friends and family wanting to "check in." This can be hard on children. You may feel supported by these conversations, but they more likely will feel uncomfortable and tired of hearing about cancer. It can help to let friends know that while you are with your children, you'd prefer not to give updates, and to set aside some "cancer free" time at home, perhaps during meals and at your children's bedtime, when you don't answer the phone.

Some families feel comfortable choosing a close friend or family member to be in charge of giving updates to everyone else, either by phone or email. One person can also be chosen to organize people who are offering to help your family. Then, when someone asks how he or she can help, and you can't immediately think of anything, you can suggest they contact your "Captain of Kindness" so when you need something they can be asked.



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When to seek professional help for your children

Most often, children cope quite well with breast cancer, despite the many challenges it brings. They continue to function mostly as usual in school and activities, enjoy friendships and are basically their usual selves at home. "Coping well" doesn't mean they don't react at all, however, because children often feel and act a bit differently when a parent is sick for a long period of time. Regression, or backsliding to an earlier developmental phase, is common for kids under stress, so depending on your child's age, you may notice things like your child needing pull-ups again at night, or being less able to talk through a conflict without name-calling, or being unable to finish difficult homework without lots of structure and help. Your child may seem less able to tolerate frustration; things that would normally "slide" create meltdowns. Or, your child may complain of headaches and stomachaches, difficulty falling asleep, or having a hard time concentrating in school. These changes generally don't last more than a couple of weeks.

However, if you notice that your child still isn't him or herself after two to three weeks, or that he or she is having difficulty in more than one area (school, peers or at home), or with adolescents, if you suspect that there is an increase in alcohol or drug use or other risk-taking behavior, then it may be time to talk with your pediatrician, a school counselor or another professional who is knowledgeable about children. It may also help to find out whether other adults, like teachers, coaches or other parents, have noticed similar changes, so you have a clearer sense of the problem.

Next steps

Coping with breast cancer, and helping your children do the same, is an ongoing process. If you want to read more about supporting children, some books you might find helpful are:

Harpham, W. (2004). When a Parent has Cancer: A Guide to Caring for your Children. HarperCollins: New York.

Heiney, Sue, Hermann, Joan, Bruss, Katherine and Fincannon, Joy. (2001). Cancer in the Family. American Cancer Society: Atlanta.

Rauch, P. and Muriel, A. (2006). Raising an Emotionally Healthy Child when a Parent is Sick. McGraw-Hill: New York.

McCue, K. (1994). How to Help Children through a Parent's Serious Illness. St. Martin's Griffin: New York.

van Dernoot, Peter (2005). Helping your Children Cope with your Cancer: A Guide for Parents and Families. Heatherleigh Press: New York.

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