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# Talking with Children about Metastatic Breast Cancer

## INSIGHT ARTICLES

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BY: Susan Fitzgerald, for *Living Beyond Breast Cancer*

The first time Adrian McClenney was diagnosed with breast cancer, she didn't tell her son. He was just starting college and Adrian didn't want to ruin his excitement or put stress on him.

She finally told her son about the cancer when she was done with treatment. He was upset that his mother had put off sharing what she was going through.

"I know you were trying to protect me, but everyone knew you were sick but me," Adrian, 45, of Miami, recalled her son saying.

That scene played in Adrian's mind three years later when, in 2014, she learned she had metastatic breast cancer. This time, she was determined to be open and honest with both her son, who is now 23, and daughter, now 13.

"My husband and I explained to her that my cancer returned. We explained that it's called metastatic breast cancer, stage IV cancer, and that I will be on medicine for the rest of my life," Adrian says. She didn't sugar-coat the seriousness of the situation, but "I tried to convey that I am going to be as healthy as I can be and we are going to continue to live life fully."

Adrian's experience illustrates what many people with metastatic breast cancer find to be one of the toughest aspects of the diagnosis — telling children or other young people that the cancer is one that can't be cured, and treatment is ongoing. Not only are you dealing with your own emotions, but you now have to figure out how to deliver news that may be upsetting and disrupt the normalcy of life. You may dread being asked the starkest of questions: "Are you going to die?"

"There is no manual to tell you how to do it," says Lori Tragesser, 45, of Tipton, Indiana, who lives with her husband and five children on an 11-acre farm. Lori was diagnosed with metastatic breast cancer in 2014.

Experts say that there is no right or wrong way to talk to kids about a diagnosis of metastatic breast cancer, though they have some ideas of what can be helpful for shaping the conversation. Tips include:

- Don't assume children, even very young ones, won't find out if you don't tell them
- Use correct, concrete words that are age and developmentally appropriate; remember, you know your child best
- Be honest but stress that your doctors have medicines that they hope will help you
- Let them know what they can expect on practical matters ("I'll be tired on treatment days, so Aunt Pat will pick you up from soccer practice.")
- Tell them you will let them know if your medical situation changes
- Be open to questions and have ongoing follow-up conversations
- Let them know there are other trusted adults they can also talk to about the cancer
- If your child is old enough to be on the Internet, suggest looking at trusted websites together. Survival statistics can sometimes be both upsetting and confusing, because the numbers are based on large groups of people and don't reflect the experiences of any one individual

"I always encourage honesty because most of the time kids can sense that something is going on," says Christina Wise, MA, GC-C, children and teen program coordinator for Cancer Support Community Greater Philadelphia. "Kids might notice that there is whispering, or that a parent goes to the other room to talk when the phone rings."

Ms. Wise also suggests not projecting too far into the future, particularly with young children who have a different understanding of time than adults do.

"I tell families, especially if it's metastatic cancer, to make it clear that while "Mom (or Dad) is sick, I am OK today. If there is a time to worry, I will let you know. But that is not today."

**Cynthia Moore, PhD**, Associate Director of the Marjorie E. Korff PACT (Parenting At a Challenging Time) Program at Massachusetts General Hospital in Boston, says that when time has passed between a first diagnosis and a diagnosis of metastatic disease, it's always good to go over with children what has already happened with the disease and what they can expect going forward. A child may need help remembering the words associated with the disease and its treatments. They may also need help understanding how the events are connected (for example, that the first breast cancer was treated with surgery or chemotherapy, but now the cancer is back and you need more treatment.)

Dr. Moore suggests trying to strike a tone that balances "honesty and hopefulness," though she said the gravity of the situation will need to be stressed if it becomes clear that the medicines aren't working for you. Hospital social workers, family counselors and clergy members, and cancer support groups can all be valuable resources for people facing that tough conversation.

Lori says that when she was first diagnosed with breast cancer in 2012 they gathered all their children, then ages 8 to 15, around the kitchen table to tell them. It felt like the right place to be because they always were together at the table for meals.

She took a different approach when she learned in 2014 that she had metastatic breast cancer in her bones. Her husband took the lead and immediately talked privately to each of the children, while she took a day to gather her thoughts and settle her emotions. “I didn’t even know what the word metastatic meant,” she says. The next day she followed up with each child to explain what was going on with the breast cancer, including that “there is no cure” and that she’d always have to do treatments.

“We wanted to be honest with them,” Lori says. “I didn’t want my kids to feel we weren’t giving them the whole truth. You want them to trust you.”

Because her family lives in a small community, Lori knew that news gets around. She didn’t want her children to learn the details of her cancer from someone else.

Lori promised her children that she would tell them if there was a change in her medical condition. When she had to switch medicines a few months ago she let them know. Her 12-year-old daughter seemed scared, asking “does this mean you are going to get sick, and what if the medicine doesn’t work?” Lori said she didn’t brush off the question. She replied, “that’s a good question and I wish I knew the answer. But if it doesn’t work, we’ll try another one.”

Another question Lori’s kids sometimes ask is if she thinks she’ll make it to all 50 states in the U.S. Her family loves to travel and already has been to 42 states. Lori tends to respond, “I can’t promise that, but we are certainly going to try.”

Ms. Wise says other trusted adults — teachers, coaches, close relatives and friends — can lend support to families dealing with difficult news. She runs support groups for kids who have a family member with cancer, and says it provides a safe place for them to open up without worry about upsetting their family.

“On the first night of the group, for some of the kids it is the first time they say the word cancer out loud,” she says.

Sarita Jordan, 47, of Philadelphia, has four children between the ages of 8 and 26, with a wide range of temperaments. Her youngest son wasn’t yet born when she dealt with breast cancer the first time. When Sarita found out in 2013 that the cancer had spread to her bones, liver, skull and lymph system, her instinct was to protect her “baby,” particularly because he struggled with his emotions at school and home.

“Stage IV is a whole different ballgame,” she says. “You’re faced with the possibility of death every day. I had to suppress my own emotions so I could help my kids.”

Her son's play therapist led the way in explaining the cancer, and that in turn paved the way for Sarita to be able to say, "Mommy has cancer." Her oldest child, 26, can get very emotional about her mom's cancer, asking "are they telling you your time is up?" Sarita has promised her kids that "I will be honest with you when the time comes."

Margaret Zuccotti, 47, turned to her experience as a teacher as she grappled with how to talk with her young kids about her diagnosis of metastatic breast cancer, which was discovered while she was nursing her third child. She had never had breast cancer before. Margaret knew that reading books was a good way to explain change to kids — whether it involved moving or starting at a new school. Two children's books proved helpful: *In Mommy's Garden* and *Butterfly Kisses and Wishes on Wings*.

"Literature is a great way to connect," says Margaret, of Abington, Pennsylvania, who started the Louise Safe Mauran Book Fund, a program at Fox Chase Cancer Center in Philadelphia that provides free children's books for families. She started a similar program, called Reading for Reassurance, for Living Beyond Breast Cancer.

Margaret says tests have found no evidence of cancer for 8 years, but her children, now 9, 12 and 15, understand that treatments and annual scans will always be part of her life.

Dr. Moore says it can be helpful for adults to make time for follow-up conversations to unfold naturally, such as during a walk or on the drive to the mall. Teens especially can stay bottled up. Words such as "If I were in your shoes, I'd be wondering if," might help stimulate a conversation, she said.

Adrian has found that the car is a great place to connect with her teen daughter and to let her know in a matter-of-fact way that a chemotherapy appointment, for instance, is coming up.

She says she realizes more each day that "I'm a lucky lady because I have a family to support me."