How To Talk To Your Kids About Your Breast Cancer

By Jamie Wells, M.D. — November 19, 2018

I had the distinct pleasure of presenting at Komen’s Pink, Purple Strength and Unity Conference on coping with a breast cancer diagnosis and how best to manage navigating such a trauma for you and your family. Topics discussed covered a wide range from optimal ways to communicate with your children, partner, loved ones, doctors and care team to how to deal with new challenges to your sexuality and intimacy. It was an incredibly rewarding experience as the day was focused around education, sharing and support-building for breast cancer survivors and individuals living with metastatic breast cancer.

In the introductory piece (read here), I emphasize taking care of yourself so you can take care of others - much like the recommendation we often hear on planes, in the event of an emergency place the oxygen on yourself before you can assist others. Here, the focus will be on how to navigate being a parent while dealing with such a disease.

How to talk to kids
They are resilient. But, they are also magical thinkers - it isn’t lying per se, but imaginative storytelling. Meet them where they are, just as they meet you where you are. When you think they aren’t listening they are. Parental denial is quite powerful even during the best of circumstances. In the absence of proactive communication, kids will magnify a snippet they overhear and can balloon a worry that doesn’t necessarily even exist. They can be quite creative linking a movie scene to their home environment, for example and in the absence of your conveying the message they are left to make up the narrative themselves. It is this often aberrant belief that is most destructive, not necessarily your actual reality.

My mother shares a story about when I was little. Apparently, I saw a statue of George Washington and responded, “He has white hair and is not alive. Poppop (my grandfather) has white hair, is he going to die?” That is rather typical thinking of a younger child. In lieu of any explanation, a child will fixate on such notions.

They can misunderstand indirect language, so being to the point appropriate for their age and stage of development is most effective. Don’t be afraid to be direct. It won’t be the direct message that will bring the lion’s share of the anguish, but the fear you bring to the discussion and the anxiety over it that they absorb. They mimic what they see, especially what they observe from their greatest rock stars (eg parents who are their first love relationship).

Talking early and often is crucial. Kids, teens in particular are naval-gazers. Teens especially spread misinformation, so without a trusted guide like a parent or adult these beliefs don’t get clarified and can foster avoidable worry.

Maintaining normalcy for them by keeping their schedule consistent is most helpful. Reassuring them without definitive promises manages their expectations while keeping an optimistic tone - let them know you have great doctors and nurses who are working hard to get you better and people can do well, treatments are improving and much research is underway. Let them know that you may not be able to do things like bath time for a bit, but trusted relatives or friends will be helping out and their needs will be met.Alerting them of how medicines may make you feel also manages expectations. Allow them to ask questions and know they always can, keeping an open running dialogue. This is not their fault nor can they “catch” it. Have conversations with the adults in their sphere (eg teachers, coaches) so you can be aware of behavioral shifts that might need addressing.

These are good rules of thumb no matter the age of a child. But older ones may require more detail given their exposure to television and other influences, like friends and social media. They likely understand the gravity of things and may need more reassurance. Always be truthful, it is the best way to nurture trust. Just like the younger ones, they need to know their needs will be met and they may place more of an emphasis on prognosis. They may be focused on death, for example, so it is important to discuss that they are loved and will always be cared for and that people are doing better and better with this disease. That new treatments are allowing people to live longer.

Sometimes because they have to assume new responsibilities, kids may feel guilty about having fun. Discuss with them that they are allowed to enjoy themselves, and you want them to do so.
Just like with younger children they will follow your lead, but don’t be surprised if they handle their emotions in sometimes hurtful ways with tantrums, for example. Sometimes they need to speak to someone who isn’t you to express their worries, their pediatrician or a close relative. Kids routinely act out as they lack the communication ability depending on their personality and age. People cope very differently too. Checking in now and again is a wonderful way to gauge things. Remember, these don’t all have to be weighty, heavy conversations. They can be surface to substance depending on the situation at hand. The most crucial aspect is you are creating an interactive dialogue that can by dynamic to suit the time - but, they build on one another and deepen understanding and trust.

**How to manage being a parent with a chronic disease**

A lot of parental guilt can cloud the situation. It is totally normal to worry that they are being forced to grow up too fast or are being denied an active, involved parent. Children unconditionally love a loving parent. The form in which that appears isn’t necessarily the motivating factor. Parents know their child and can identify their most meaningful needs. When these are met, even in a new way kids can find comfort in the routine. Maybe you can’t walk them to school each morning, but you can Facetime them the whole way or create something special as they leave and return each day. Maybe you create a movie time or part of the day when it is just the two of you.

With older children, empowering their autonomy can help them feel useful and take pride in their efforts. Maybe for some that is giving them the responsibility of meal preparation. On days you can do it together, they can take a lot of pride in the experience and it will be a bonding, memorable time for all. It is nurturing and worthwhile. For other kids, it can be having the responsibility of getting the mail.

Speak to your child’s pediatrician. They can connect you with other patients going through such a diagnosis as a parent of an infant or otherwise. They can also help you identify your child care needs, call you after each appointment you cannot attend so you are always in the loop and even accommodate an off hour visit if so required. If your doctor or your child is not asked, then they can’t know. How that manifests can be a call, a written note or whatever brings you the most comfort in addressing the uncomfortable topics.

There are a number of organizations in your community that can help with quality of life measures like a meal delivery service or managing child care. Support groups abound of women in your situation who might have great tips to ease burdens. Your care team can help direct you.

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