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Talking to Children about Cancer

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A cancer diagnosis is a challenge for any family. Suddenly you are struggling to understand your diagnosis, weigh treatment options, make choices about your medical treatment team, and manage appointments. It is often an emotional roller coaster of shock, anxiety, sadness, and worry. It can be a good idea to engage partners, family, and close friends in helping with the practical concerns and emotional upheaval. Some people think it is a sign of weakness to seek help. I always see it as a sign of strength, and caring, both for the parent and for the child.

Children are sensitive to emotional changes and will pick up on the new atmosphere in the household so it is important to think about how you will talk to them about this news. Sometimes parents want to protect children from the situation and keep it a secret. But kids have what I think of as "emotional radar" and will know something is wrong. Often what they imagine will be worse than the reality. Children also tend to see themselves at the center of things, and may blame themselves for everything from cancer to divorce, so it is important to give them clear information about what is happening.

Each child is different, and the information shared should be tailored to the child and to her or his developmental level. Before sharing the news with your child, it is important to understand your own emotions and to have enough information and emotional support to speak calmly and clearly. Think through what you wish to say, and whether you wish to have a partner present for the conversation.

Children's developmental levels and personalities vary, but there are some basic guidelines that may help. Use the word "cancer" and explain it in simple terms of good healthy cells that all of us have, and the destructive cancer cells that are causing the illness. Reassure them that there are many kinds of cancer and many doctors who treat cancer. Explain that you have chosen a very good doctor who has a plan to help treat your cancer. It is very important to tell kids that you cannot "*catch"* cancer from another person, *ever,* or "*give"* cancer to anyone.

You can be descriptive without going into unnecessarily complex medical information. It is useful to tell children where the cancer is affecting your body, and how it will be treated, using straightforward terms for parts of the body. For a younger child, pointing it out on a doll or

stuffed animal could be helpful. Kids will overhear things anyway, and it is important to be truthful so they know your information can be trusted.

Chemotherapy can be simplified to “very strong medicine” for a younger child. Let the child know if you will be staying at the hospital for surgery. This is also a good time to reassure your children that they will be taken care of, even if you are not as available to care for them. Radiation can also be explained as special treatments that destroy the bad cancer cells so that the healthy cells can live.

Children hear the “music” as well as the words, so try to be reassuring and hopeful even though this is difficult for you to talk about. Kids are also resilient, and having information helps them to make sense of things. Sometimes older children know about cancer, through friends or television or books. They may need to be reassured that you expect the treatment to work, and that you will do everything you need to do to try to get well. Self-centered thinking is natural in kids, so it is not surprising when they ask about their own basic needs and routines. Try to provide as much continuity and structure as you can, but also let them know that everyone may need to be flexible. It can be tempting to allow special treats like staying up late, or new toys as distractions. But, maintaining the usual and normal routine is actually the most reassuring approach.

Side effects are good to talk about before they happen. Letting children know that you may be tired, or that you expect to lose your hair, is difficult, but much better than letting this come as a surprise or trying to hide it. This is also the time to let them know that your hair will grow back and that the medicine that will make you more tired or nauseous is the strong medicine that will destroy the cancer cells and help to get you well again. One young child I worked with explained this to me as the good guys killing the bad guys, so mom would get well.

Be prepared for questions. Answer simply but honestly. It is also OK to say if you don’t know something that you will find out and get back to them with an answer. Especially difficult are questions about survival when there may be some uncertainty, and you yourself are very worried. Words like “hopeful” and “doing everything my doctor can think of to get well” can work well here. Let your child know that you will be trying hard to get better. You may have many chances during treatment to remind your child that your fatigue, nausea, or hair loss is a sign that the strong medicines are working hard to kill the bad cancer cells.

Children may need new ways to be close to you while you are being treated, or recovering from surgery or treatment. I have worked with families who began reading together in bed, or watching family movies when other activities were too tiring or a parent having chemo needed to avoid outside crowds. One family created bedside picnics to include the resting parent at dinnertime. Older kids and teenagers may need to be encouraged and know that it is all right to have fun with friends and be busy with their own lives.

All of the adults in your child’s life should be on the same “page” and providing consistent messages. This goes for spouses, life partners, parents, siblings, close friends, teachers, clergy, etc.

I have found most teachers and school staff to be supportive of children going through a very stressful time of family illness. Consider letting your child's teacher and the school's guidance counselor know that you are being treated for cancer. Depending upon the age of the child, this is often best only after you have first told your child that you will be sharing the information with the school. School is a large part of a child's world, and a simple "how are you?" that recognizes that things are difficult at home can let a child feel cared for at school. Specialized school staff can become involved if necessary. Some families I have worked with have found it very helpful for the child to have a person at school they can confide in, whether it is their teacher, guidance counselor, the school nurse, or school psychologist.

One child I worked with had stopped eating her lunch, until a sensitive teacher noticed and found out that she was worried about her mom in the hospital. After checking with the parent, the school arranged for the child to make a short phone call to the parent at lunchtime. Hearing her mother's voice was reassuring, and this little girl was able to eat lunch and go about her school day again.

In my practice, I often see children who are having an especially hard time with a medical situation, but it is always good to consider whether your child or you may need expert advice or support. If a child is having continuing difficulty sleeping or shows changes in eating, is distressed at school or having new problems with friends, consider a consultation with a psychologist experienced in this area. Psychologists working with health issues and expertise with children may help the child express and cope with their feelings. The psychologist may suggest ways for the parents to help the child during this stressful time.

Other good resources include The American Cancer Society website and your state Psychological Association website. Your treatment facility may offer support groups for parents, life partners, and children, especially if you are being treated at a cancer center. Many large hospitals have psychologists, clinical social workers, and child experts on staff who can be good sources of guidance, and also offer books and online resources for parents and children. CancerCare® is a reliable website providing links and resources for children of different ages. For breast cancer, I like www.breastcancer.org, a website covering many issues with archived webcasts and expert interviews on talking to children about cancer. Magination Press, by the American Psychological Association, publishes several books for children of parents who have cancer.

In conclusion, do not be afraid to talk to kids about cancer. It is far more important that they hear about what is going on from you. Much like the advice given to passengers on airplanes to "put your own oxygen mask on before you help with your child's," you will need to take care of yourself and your own anxiety and other feelings first. Then, you can go on to help your child effectively learn to cope with your diagnosis and treatment. Helping your child understand cancer at an age appropriate level is essential to helping them cope during a difficult time for any family. With information and emotional support, your child will be able to communicate their own concerns and needs as their parent navigates the difficult experience of serious illness.