

Facilitating Communication

A Guide for Parents

Parent-child and child-parent communication is an essential part of supporting children through a parent's cancer care. Listening to your child or teenager is just as important as talking with him or her.

Here are some ideas about starting the conversation and keeping it going at different stages of care.

Work Up & New Diagnosis

Start a conversation...

Most parents know times when their child or teen is most likely to engage in quality conversations. You may want to prioritize these times to make the space for valuable communication to occur.

Ask what your child has noticed?

You can start the conversation by identifying something that your child may have noticed, such as pain you have complained about or a visible physical symptom. More obvious may have been disruptions to the usual schedule because of doctors' appointments, increased phone calls to your home, or visits from family members.

For example, you might say, *"You know that I have been complaining about having so many headaches. I don't know if you also noticed that Grandma and Uncle Scott having been calling us a lot lately or if you have noticed other changes with me or around our house?"*

Knowing what your child has noticed or heard helps you know where to start the conversation about your diagnosis or about the assessment that is underway. You may also uncover important misconceptions that need to be corrected with more accurate information. This is important because confusion interferes with coping.

You might think about this initial conversation as the beginning of a collaboration with your child to write a "story" about your cancer that will make sense to your child and encourage continued talking and understanding together. Your child is seeing and hearing things. Imagine that this is like the pictures in a book. You and your child can write the text together for your family cancer book to accompany these pictures. Engaged conversations enable the narrative to be honest, loving and consistent with your family values.

Name your type of cancer.

Explain that you have been working with a doctor or medical team to understand your symptoms or findings from an X-ray. If you know your diagnosis, share it with your child. For example: *"After several special tests, the doctor told us that I have breast cancer."*

Ask if your young child knows what cancer is?

Be ready with an explanation that is suited to your child's age. For example, for younger children: "Our bodies are made up of millions and millions of tiny cells like Legos that are so small that they can only be seen with a microscope. Cancer cells are mixed up Lego cells that do not fit together right and cannot do their jobs. They also get in the way of other healthy Lego cells that are trying to do their jobs."

An explanation for older children might include talking about cancer cells that are dividing and growing too rapidly and sometimes create a tumor in one place and sometimes travel to other locations in the body. Healthy cells divide too, but cancer cells have an error in their on/off switch and make too many copies of themselves which interfere with the healthy cells and functions in the body.

Ask if your child knows other people who have had cancer: who, when, and what specifically does your child know about that person's cancer experience?

It is helpful to know what your child knows about another person's cancer experience, because your child or teenager may assume that your medical condition will unfold in the same way. Let your child know that cancer is different from person to person and depending on where in the body the cancer cells originate. You want your child to know that the only way to know about your cancer and its response to treatment will be to talk with you and your co-parent or other key close adults.

You might think about using the analogy that just like there are many breeds of dog, there are many breeds of cancer—where the cancer started is like the breed. Different cancers are treated differently. Even in the same breed, one dog might be friendly and another aggressive. As you get treatment for your specific type of cancer, you and your medical team will be determining how friendly or fierce your cancer is.

If your child asks about prognosis, you may want to let them know that the medical team will know more after you receive treatment and do follow up testing. Let your child know you will share new information when you have it.

Older children and teens may seek information on the web. For adults and teens, information on prognosis can be overwhelming and misleading. Encourage your child to seek information about you from you and based on the specifics of your individual treatment. If they do get information elsewhere, encourage them to share it with you so it can be processed together.

One way to talk about research findings on cancer is to use the analogy of a stadium full of individuals. The information reported in a research study that examines outcomes for a particular diagnosis is an average of everyone, not data on one individual. For example, think about all the people attending a baseball game in a large sports arena. The average age of people attending the game might be 37, but in a particular seat in the stadium the person might be 6, 36 or 86. Data reported on everyone with a diagnosis getting a specific treatment is not specific to you and does not account for your response to treatment.

Cancer Treatment Begins

Tell your child what you know about your upcoming treatment.

Depending on what your treatment plan includes, explain what surgery, chemotherapy, radiation or immunotherapy is. Invite your child to ask questions. As you go through treatments, continue to share more information including side effects or other changes in you that might be noticed.

Ask what about this upcoming plan worries you or is confusing?

Remember that each child may have individual concerns and the best way to uncover these is by asking. Let your child know that you respect that each family member will be adjusting to their own special challenges with schedule changes, additional adults helping out, and their separate life events happening. When children and teens share their personal perspectives and priorities, it is much easier to create plans that are as good for each as possible.

One way to communicate this idea is to encourage your child or teen “not to worry alone”. Remind your child that sharing worries or distress allows you to problem solve together which works much better. Teens may relate to the idea that worrying with you will be much less “annoying” than leaving you to worry about him, because worrying about someone without their input more often than not misses the mark.

Treatment is Underway

Often the first treatment is hardest to plan for because it is hard to know how you will feel on treatment days, how long you will be away from home, what kind family or community support would be most helpful and how this will affect your time with your children. Many parents find that they can prepare themselves and their children better after the first treatment, because they know what to expect.

Be sure to update your children at each stage of your treatment especially when there is a transition.

By regularly sharing updates about the status and current goals of your treatment, you are ensuring that if your cancer does not respond to treatment as hoped, your children will not face sudden and unexpected news. They will know that you have tried different treatments and that the cancer has unfortunately grown through the treatments.

Ask what your child thinks went well or could have gone better?

The best plans are ones that keep getting adapted with experience and include multiple family member perspectives. Much of the wisdom about how to adjust schedules and support each other emotionally comes from having experience and communicating openly about it.

You might talk about engineering a coping plan as being like a prototype for a new machine. Engineers start with their best guess of how to make the machine perform the desired task. Then they try it out and make changes to improve it. Some children and teens know that this is the process that videogame designers go through. Starting with a “best guess” of what will work well and then improving it with experience is a great model for individualized coping plans.

Ask if your child feels she hears too much, too little or the right amount about your cancer treatment?

A good rule of thumb about what information to share with your child or teen is anything that causes a change in plans, anything that affects the child's own schedule directly, significant new information such as a scan result or anything that your child might be likely to overhear others discussing or learn from someone else. Your child's age and temperament will affect the ways communication about your treatment may be adapted through your conversations together about what feels like the right amount of information for the child.

Ask if friends or other grownups have asked your child about your cancer care or have said things to him about it?

Some children will spontaneously share comments made by peers or adults and others will not. Those children or teens who do not talk with you about these interactions may be upset by what was said but be reluctant to share it with you, while others may not feel it is sufficiently important to tell you about. In either case, it can be a conversation starter to learn what your child has been hearing from others and how the comments are interpreted by your child.

Ask what your child's friends might not "get" about having a parent with cancer because your child's friends are not living it?

Encouraging your child to voice what has been learned through "lived experience" helps you understand more about your child's unique perspective and unfolding experience. You may find that this vantage point is what you had imagined, or you might be surprised by what your child identifies as learned from the real experience. These conversations can be opportunities to talk about being understood or misunderstood by peers and about how to be a good friend to others facing similar or different challenges.

Some older children and teenagers may find it easier to answer the question, "What is the dumbest thing anyone has said to you about my cancer diagnosis or treatment?" Sometimes, it is easier to be annoyed than to let in the sadness or vulnerable feelings associated with a hurtful comment. Humor can open a door to talking about difficult conversations as long as you are careful not to let your teenager feel you are making fun of her reactions or thoughts.

Make open communication about any topic part of your family environment.

Encourage your child to talk about all the aspects of daily life. It is important for children to know that you are interested in their routine childhood concerns that do not related to your cancer. Let your child know you like to hear about the positives of their day or week as well as the challenges. It is important to have cancer-free conversations with your child. This often feels good to parents and their children. Many parents find that having hard conversations about cancer sets the stage for honest sharing about the many other challenges faced by children and adolescents.

Some children will respond well to having a daily ritual of asking: what was your favorite thing you did today?, what was the hardest thing about today?, and what did you do today that you are most proud of? Parents can also share their favorite, hardest, and most proud daily experiences to model self-awareness and sharing.