How A Child Understands Cancer

This section has been reviewed and approved by the Cancer.Net Editorial Board [1], July / 2012

Key Messages:

- Although parents want to protect their child from fear and other difficult feelings, parents should be specific when discussing their child?s medical condition with their child, even if the child is very young.
- The amount of information and details about the cancer that you share with your child depends on his or her age and what you think he or she can understand.
- Try to keep the lines of communication open, as you will likely need to have several conversations with your child.

For most parents, few things are as frightening as being told that your child has cancer. At a time when parents are dealing with their own fears and confusion, they must also face the responsibility of helping their child understand his or her cancer.

Whether to tell your child he or she has cancer

Many parents think they can protect their child by not telling him or her about the cancer diagnosis. However, it is important to identify your child?s medical condition as ?cancer? and then further describe it (for example, as leukemia, sarcoma, or a brain tumor), especially if your child will hear this language from others. Identifying a child?s illness as cancer is important. It helps build trust with your child, enables your child to ask questions, helps him or her feel included in the surrounding medical conversations, decreases confusion, and prevents your child from learning the diagnosis by overhearing it from someone else. Your child is also more likely to cooperate with the tests and treatments.

Children who are not told about their cancer use their imagination to fill in the knowledge gaps. For example, they may think their illness is a punishment for bad behavior or that they did something to make themselves sick. Furthermore, not knowing what is wrong or what to expect may cause your child excessive anxiety, stress, and fear. Most children already know that something is wrong. They may not be feeling well or may wonder about frequent visits to the doctor or hospital.

What to tell your child

What you tell your child will depend on both his or her age and what you think he or she is capable of understanding. The following information briefly describes what children of different ages are likely to understand at each stage of development:

Ages 0 to 3

- Cannot understand cancer
- Are most afraid of being separated from their parents and of medical procedures they cannot understand
- Need to be reassured that you will not abandon them at the hospital
- Although young children have no way of anticipating or understanding a procedure or trip to the hospital far in advance, they still should be told of upcoming events in simple, clear, and reassuring language.
- Preschoolers may have fears that they will live in the hospital forever and worry about finding ways to leave the hospital. Tell your child that no one lives in the hospital forever and when treatment is done, he or she can return home (if that is indeed the situation). If you know how many more days your child will be in the hospital, you may share that information, too.

Ages 3 to 7

- Understand cancer explained in simple terms
- Look for a specific cause for their cancer, such as something they did or thought
- Need to be reassured that they did not cause their cancer
- Need reassurance that you will not abandon them
- Again, preschool-aged children may fear that they will end up living at the hospital, so it important to let your child know he or she can return home (see above).
- Kids at this age are afraid of pain and of being hurt. Be honest with your child about tests and procedures that may hurt, but also explain that the treatment is being done to help make them better. You may also explain that doctors can help make procedures less painful.

Seven to 12 year olds

- Are capable of understanding a more detailed explanation of cancer
- Are less likely to believe that their cancer was caused by something they did

- Are more likely to understand that they will need to take medicine and undergo other treatments to get better
- Are afraid of pain and of being hurt; therefore, be honest with them about tests, treatments, and pain management
- Kids this age will likely hear messages about cancer from other sources, such as school, TV, and the Internet. Try to encourage your child to share any information he or she learns with you so that you can discuss it together, instead of having your child worry alone.

Teenagers

- Teens can understand a complex explanation of the cancer and may have many detailed questions. They may be interested in learning more about their diagnosis.
- They are most likely to think about their cancer in terms of its symptoms and its effects on their daily activities, such as school, sports, and relationships with friends
- Like the previous age group, your teen will likely hear messages about cancer from a variety of sources. Do your best to ask about any information your teen is getting from other sources or to learn about your teen?s specific fears so that you can discuss it together and/or with members of the health care team.
- Are capable of understanding the relationship between their symptoms and cancer and the role of treatment
- May want to be involved in making decisions about their treatment
- Teens often have a unique set of concerns surrounding their physical appearance and their ability to fit in with others [2]. They may be concerned about losing their hair and gaining or losing a lot of weight. Talk honestly with your teen about the possibility of other side effects.

Points to remember when talking with your child about his or her cancer

- Practice what you are going to say beforehand and ask for advice from your child's doctor, nurse, social worker, or another parent who has been in a similar situation.
- When you first talk with your child, consider asking another person to be with you. This might be another family member who can provide emotional support or a doctor or nurse who can help describe cancer in detail.
- A single conversation with your child probably won't be enough. Have frequent, brief conversations with your child to keep the lines of communication open.
- Be open and honest and encourage your child to ask questions. Answer questions honestly, even if this means you don't know the answer and need to follow up later.
- Share your feelings with your child and encourage them to share too. You are your child's most important source of information and support. If they think they can't share their feelings with you, they may think they can't share them with anyone and may feel completely alone.
- Explain the meaning of cancer-related words your child may encounter at the doctor's office or hospital in a way they can understand. For example, an x-ray is "a picture of the inside of your body," chemotherapy is "special medicine to get rid of the cancer," a tumor is "a lump inside your body." Learn more about basic oncology terms [3].
- Talk with your child about the treatments they will need and what will happen during the each treatment. Be honest about the possibilities of pain and other side effects. Learn more about preparing your child for medical procedures [4].
- Seek support for both yourself and your child. Sources of support include hospital social workers, support groups [5], individual and family counseling [6], and religious or spiritual resources.

A special note on talking with your child about death

Although the majority of children with cancer survive this disease, not every child will recover from cancer. Some parents are faced with the challenge of helping their child prepare for death. Each family has its own beliefs about death, and how and when you talk with your child about death and dying is a personal decision. Children also need to know that they will not be alone. Read more about caring for a terminally ill child [7].

More Information

Guide to Childhood Cancer [8]

Cancer in Children [9]

Cancer in Teenagers [10]

Additional Resources

National Cancer Institute: Young People with Cancer: A Handbook for Parents [11]

Links:
[1] http://www.cancer.net/about-us
[2] http://www.cancer.net/node/25145
[3] http://www.cancer.net/node/24928
[4] http://www.cancer.net/node/24652
[5] http://www.cancer.net/node/25383
[6] http://www.cancer.net/node/24699
[7] http://www.cancer.net/node/25280
[8] http://www.cancer.net/node/18689
[9] http://www.cancer.net/node/25114
[10] http://www.cancer.net/node/25116
[11] http://www.cancer.gov/cancerinfo/youngpeople