Helping Children Cope When Someone They Love has Cancer

Knowledge is Power

SCCA Patient and Family Education Department
Important Common Concerns and Fears
Even if your child does not ask these questions, they may wonder...

Will I get cancer?
Cancer is not contagious. You cannot “catch” cancer.

Did something I do cause the illness?
No. Cancer can just happen. Scientists are doing research to understand this better, but we know nothing you (the child) did or thought caused the cancer.

Is cancer treatment a punishment?
No. Cancer treatment is not a punishment. It is a way to get rid of bad cancer cells in the body. Even though it can make you feel bad for a while, it makes your body healthier in the long run. A conversation about cancer cells is often helpful to help children understand the way treatment works. For example, “Your body is made up of tiny building blocks called cells. Cancer happens when cells grow too fast and makes other cancer cells too quickly. This makes the body not work right. Chemotherapy kills these fast growing cells. During surgery, the doctor takes out the group of cancer cells (tumor). Chemotherapy can affect other fast growing cells in the body such as hair cells and cells in the stomach, this is why a person may lose their hair and feel sick to their stomach during treatment. They will feel better and their hair will grow back after the chemotherapy treatment ends.”

Depending on the child’s age and his/her experience with cancer, he or she may wonder...

Are you (or my loved one) going to die from cancer?
Your answer to this question will change based on the child’s age, your family’s beliefs, and your situation. A social worker or other health professional can help you sort through this. For example, “We are working very hard for (the loved one) to get well. I will let you know if this changes or if I am worried about (the loved one) dying. I also want you to tell me when you are worried. What would you worry about most if (the loved one) died?” A child may have specific fears that he or she wants to talk about (“Where would my room be? Who would watch me after school?”).
Suggestions for Communication: When and How Much?

You know your child best. How you talk with your child about cancer will vary based on your knowledge of your child and your family’s culture, faith, and beliefs about cancer. People have many myths about cancer and treatment. Stay with the facts.

- First, learn what you can about the illness, including side effects and the schedule of treatment, so that you are able to prepare the child and answer their questions about what to expect.
- Choose a time to talk to your child when you feel you can calmly discuss the illness and support your child with his/her emotional reaction. Your child may be upset by the information or he or she may have very little reaction. Children often need to absorb this information over time.
- Children can usually sense when something is wrong and often imagine the worst if they do not know what is happening. Teaching children early about your diagnosis helps them feel included and helps them understand the changes they see.
- Invite a professional or a close family member to help prepare you mentally and emotionally. If needed, they may help you discuss the illness with your child. You or another loved one should be with the child for support and security if another person provides the information.
- Begin with what the child sees and knows: “You know how your aunt has been grouchy and sleeping a lot?”
- Use the actual name of the disease, including the word “cancer,” so the child becomes familiar with it. This will help them feel prepared for the terminology they will hear from others.
- Remind your child that there are many different types of cancer and treatments. They may think exactly what happened to another relative or friend with cancer will happen to you. It may be very different.
- Use developmentally appropriate language they can understand (see Age Considerations section) about where in the body the disease is, how the disease will be treated, and how this will affect their life, including changes in family system.
- Children will vary in how much information they want to have and can cope with; the goal is to give enough information that will address their fears and give them a sense of security in the midst of the upcoming changes. Allow them to guide you with how they are feeling.
- Be truthful about things you cannot answer or offer, sometimes an assurance that everything will work out well is not possible. Assure them that they will be taken care of no matter what, and use this opportunity to tell your child about how you cope with the unknown.
• Encourage your child to ask questions. You may need to answer the same question many times.
• Try to help your child draw out his/her feelings (e.g. adult says, “When I feel sad I....”, then asks child to draw picture of that emotion and talk about a time when they felt that emotion).
• If it’s a parent that’s ill, tasks to help that parent (making them a picture, etc.); making “books” for younger sibs about illness; scrap-booking about experience; asking how/if they would like to help the family.
• Journaling; scrap-booking; talking about best and worst parts of each day.

Meeting your Child’s Needs

First and Foremost: Take Care of Yourself:

• It is extremely challenging to parent and to manage cancer treatment and side effects
• Recognize your limits and adjust expectations of yourself.
• Set aside time every day for yourself.
• Eat healthy foods.
• Maintain physical activity and get enough sleep.
• Allow people to help, and have a list handy of specific things others can do.
• Utilize friends, family members, support groups, and professionals for emotional support.

Children’s Emotional Needs:

• Be open to discussion, anywhere, anytime. Children may have a question when you least expect it.
• Allow your child to see the treatment clinic or hospital if they show interest in going. Prepare them for what to expect there before the visit.
• Your child will cope with this in his or her own unique way. Ask how they are doing and look at their behavior for clues.
• Your time is one of the greatest ways to show your love, make one-on-one time a priority for each child.
• Allow the child to “help” in ways that are meaningful to them. For example, drawing a get well picture, talking with the loved one about the best and worst of his or her day, filling the loved one’s water pitcher each morning, etc.
• Maintain fun family times as possible, make special adapted plans for holidays or events.
• Discuss changes in routine and what the child can expect.
• Let others help to fill in gaps, such as a trusted uncle or aunt going to the soccer game.
• Invite fun, imagination, and interactive play into everyday activities. For example, an in home “picnic” at meal time, comedy movies at night, or a new craft for family members to work on together.

Children’s Social and Developmental Needs:

• Help the child maintain as much contact as they can with friends, family, and others they care about (in person, writing, phone, email).
• Maintain learning opportunities and structure through formal school or tutoring.
• After discussing it with the child, alert school counselors and teachers about the situation and the child’s current needs.
• Discuss any family privacy issues and expectations with your family members, what is and what is not okay to talk about outside of the family.
• It is normal for your child to act younger and test limits during this period. They may be looking for attention from you or a clear sense of safety and security during this period.
• Discipline is hard to maintain, but is very important to help your child continue to develop and function well with family, peers, and school during and after treatment.
• Set clear expectations for the child during treatment and transition times. Rules may need some flexibility during stressful periods (e.g. bedtime). Discuss any changes with your child.
• Involve all caretakers to maintain as much consistency in the child’s care and discipline plan as possible (e.g. Grandma’s rules similar to Mom’s).
Age Considerations
Please keep in mind that your child may fit into part of or more than one of these groups:

Preschool Age Children (approx. 3-5 years old)

- Tend to be egocentric; believe that the world revolves around them and care mostly about how the illness affects them.
- Inclined to have magical thoughts; think they have the power and ability to control things (e.g. think they can cause someone’s illness by having bad thoughts about that person or by misbehaving).
- Tend to understand well when dolls, pictures and books are used to explain things.
- Need reassurance that someone will always be there to take care of them.
- May react with sadness or may seem indifferent.
- May react to illness by having behavior problems (e.g. will act out more for attention) or acting younger in terms of development (e.g. bedwetting, clinginess).
- Are good at expressing feelings/emotions through play and sometimes need help identifying feelings.
- Often believe that death is reversible and that a person who has died will/can come back.

School Age Children (approx. 6-11 years old)

- May want to do some research about disease on their own.
- Start to understand that death is permanent.
- May want to know more about treatment (e.g. side-effects, physical changes).
- May react by being sad, mad, and/or irritable; have physical complaints or headache, stomachache, etc.; may be angry towards sick loved one; have poor concentration; or have difficulty adapting to changes in routine.

Teenagers (12 years old and above)

- Adolescents are capable of abstract thinking; understand ethics and ideas they cannot see.
- Tend to have a need for independence.
- Can sometimes deny feelings to avoid talking to you about them.
- Are capable of thinking like adults.
- May want a lot of details.
• Try to encourage them to talk about their feelings, but realize they may be more comfortable talking to a friend, a professional, or another trusted person.
• Try to assure them that you want them to have normal activities outside of the family.
• Watch for signs of them trying to take on too much responsibility or parenting younger sibs.
• May react with anger, rebellion, depression and anxiety, withdrawal, physical symptoms such as stomachaches and headaches, keeping feelings to themselves.

References for More Information
*Many of these items can be found in the Patient and Family Education Resource Center and Library

• Art with Heart (Seattle-based group that uses art therapy to help kids deal with crisis), artwithheart.org
• When Your Parent has Cancer, A guide for Teens, National Cancer Institute

Other Recommended Readings
For the Parent:

• How to Help Children Through a Parent's Serious Illness, by Kathleen McCue, with Ron Bonn
• Can I Still Kiss You? Answering Your Children's Questions About Cancer, by Neil Russell
• When a Parent Has Cancer: A Guide to Caring for Your Children, by Wendy S. Harpham
• Frankly Speaking about Cancer, What do I tell the Kids, Cancer Support Community, www.cancersupportcommunity.org

For the Child (to read with the adult):

• When Someone You Love Is Being Treated For Cancer, by the National Cancer Institute
• Tickles Tabitha's Cancer-Tankerous Mommy, by Amelia Frahm, Elizabeth Schultz (Illustrator)
• What Is Cancer Anyway? Explaining Cancer to Children of All Ages, by Karen L. Carney
• Sammy's Mommy Has Cancer, by Sherry Kohlenberg, Lauri Crow (Illustrator)
• The Year My Mother Was Bald, by Ann Speltz, Kate Sternberg (Illustrator)
• Because Someone I Love Has Cancer: Kids' Activity Book, by American Cancer Society
• *Talking with my Treehouse Friends about Cancer*, by Peter R. Van Dernoot
• *Life Isn’t Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer*, by Pam Ganz
• *When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change*, by Marge Heegaa
• *You are the Best Medicine*, by Julie Clark
• *The Invisible String*, by Patrice Karst

Questions? How to Contact Us

• Seattle Cancer Care Alliance 206-288-1000
• Patient and Family Services 206-288-1076
• Patient and Family Education Resource Center 206-288-2081
• Child Life Specialist – 206-288-7621