This packet offers information to help your child understand what’s happening when you or someone else they love has cancer. It also offers ways to help them process their thoughts and emotions.

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Common questions your child may ask

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

Did something I do cause the cancer?
No. Cancer can just happen. Scientists are doing research to understand this better, but nothing you 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. 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.”

Are you going to die from cancer?
Your answer to this question will change based on your 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 me or <name of loved one> to get well. I will let you know if this changes or if I am worried about <name of loved one> dying. I also want you to tell me when you are worried. What would you worry about most if <name of loved one> died?”

A child may have specific fears that he or she wants to talk about, for example:
“Where would my room be? Who would watch me after school?”

When and how much do I tell my child?
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. Stick with the facts. Here are some suggestions for talking to your child.
When to talk to your child

- Talk to them early. Children can usually sense when something is wrong and often imagine the worst if they don’t know what is happening. Teaching children early about your diagnosis helps them feel included and helps them understand the changes they see.

- While teaching your child early is important, try to learn as much as you can about the illness and treatment plan, including side effects and the schedule of treatment. This will help prepare you to answer their questions.

- Choose a time to talk to your child when you are calm. This will help you support your child with their emotional reaction. Know that your child may be upset by the information or hardly react at all. Children often need to absorb this information over time.

- Invite a professional or a close family member to help prepare you mentally and emotionally for a conversation with your child. 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.

How to talk to your child

- Begin with what the child sees and knows, for example: “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 age-appropriate language they can understand 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. See Age section of this handout for more about this.

- The amount of information children want versus what they can cope with varies. Your goal is to give enough information that will address their fears and give them a sense of security amid the upcoming changes. Let their feelings to guide you.

- Be truthful about things you cannot answer or offer. Sometimes telling them that everything will work out well is not possible. Make sure they know that they will be taken care of no matter what. 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.
Activities for your child

It may be helpful to have your child do something to help them work through their emotions. You can ask your child to:

- Draw a picture that completes this sentence: “When I feel sad I....” Your goal is to get them to draw the emotion and tell you about a time when they felt that way.
- Journal or scrapbook about their experience. They can include the best and worst parts of each day.
- Create artwork (draw or paint a picture, for instance) for their loved one who is ill.
- Make “books” about the illness for their younger siblings.

Meeting your needs

First and foremost: Take care of yourself

It is extremely challenging to parent and manage cancer treatment and side effects. Take care of yourself by doing the following:

- Recognize your limits and adjust expectations of yourself.
- Set aside time every day for yourself.
- Eat healthy foods.
- Stay active and get enough sleep.
- Let people help you; keep a list of specific things others can do.
- Lean on friends, family members, support groups, and professionals for emotional support.

Meeting your child’s needs

General

- Be open to discussion, anyplace, 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 before the visit.
- Your child will cope with this in their 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 your 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 their day, filling your water pitcher each morning, etc.
• Maintain fun family times as possible. If you need to, create special, adjusted plans for holidays or events.
• Discuss changes in routine and what your child can expect.
• Let friends and family help fill in gaps, like going to your child’s soccer game.
• Make everyday activities more creative and fun, for example: have a home “picnic” at meal time, watch funny movies at night, or work on a family art project together.

Social and developmental

• Help your child maintain as much contact as they can with friends, family, and others they care about (in person or by phone, text, email or letters).
• Maintain learning opportunities and structure through formal school or tutoring.
• After discussing it with your child, alert school counselors and teachers about the situation and your child’s current needs.
• Discuss any family privacy issues and expectations with your family members. Let them know what is and is not okay to talk about outside of your 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 your child during treatment and transition times. You and your child may need to be flexible with rules and routines during stressful periods (for example, bedtime).
• Discuss any changes in rules and routine with your child’s caregivers. It is important to maintain as much consistency in your child’s care and discipline plan as possible. For example, grandparents, rules and routines should be similar yours.
Age

This section offers insight into how your child may process information based on their age and stage. Please keep in mind that your child may fit into part of or more than one of these groups:

**Infant and toddler age children (birth-2 years old):**

- Do not understand the concept of illness; however, do notice physical changes in caregiver, for example: hair loss, nausea, vomiting, mood changes.
- React to caregiver’s emotions; can sense and respond to caregiver’s anxiety, sadness, stress, etc.
- May develop changes in their eating/sleeping habits, mood and skin related to stress, for example: develop a rash or be difficult to soothe.
- Notice and be sensitive to changes in routine; notice caregiver’s absence and/or the presence of an unfamiliar adult. Try to have infants/toddlers cared for by trusted adults that are familiar to them.
- Leave them with a familiar blanket or object to ease separation anxiety.
- Give infants/toddlers lots of physical contact, for example: hugging and holding.
- If infants/toddlers are stressed or irritable, try to calm them with soft, relaxing music.

**Preschool age children (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, for example: think they can cause someone’s illness by having bad thoughts about that person or by misbehaving.
- Are good at expressing feelings/emotions through play and sometimes need help identifying feelings.
- 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, for example: will act out more for attention or act younger in terms of development, for example: bedwetting, clinginess.
- Often believe that death is reversible and that a person who has died will/can come back.

**Grade school age children (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, for example: side-effects, physical changes.
- May react by being sad, mad, anxious and/or irritable; have physical complaints or headache, stomach ache, and more; 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.

Resources

The resources below were used to help create this handout. They may be helpful to you. Many of them can be found in the Patient and Family Education Resource Center on the 3rd floor of the SCCA South Lake Union clinic.

- Art with Heart | Seattle-based group that uses art therapy to help kids deal with crisis artwithheart.org

Other resources

For adults

- *How to Help Children Through a Parent's Serious Illness*, by Kathleen McCue, with Ron Bonn
- *Frankly Speaking about Cancer, What do I tell the Kids?* Cancer Support Community, cancersupportcommunity.org
- *When a Parent Has Cancer: A Guide to Caring for Your Children*, by Wendy S. Harpham
For children
We recommended that you or another adult read these with your child.

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

Questions?
Please call SCCA’s Child Life Specialist at (206) 606-7621 with questions or concerns.