

2

TALKING TO YOUR CHILD ABOUT CANCER



Talking to Your Child About His or Her Diagnosis. Regardless of age, children are usually aware when their health causes their parents concern. Your child may experience a variety of emotions, such as anger, guilt, fear, anxiety and sadness, all in quick succession.

Sometimes parents wish to shield their child from information about the illness and its treatment. Keep in mind that your child will use his or her imagination to fill in perceived gaps of information.

Talk with your child about the illness and its treatment. Listen carefully to what your child is saying (or not saying) and then answer his or her questions. Be sensitive to your child's body language and other reactions. These conversations are key to building trust. Your child is more likely to let you know when something is scary or worrisome if he or she trusts you. You can take this opportunity to address some of those fears and concerns.

Acknowledge that receiving a cancer diagnosis can lead to many types of "losses," such as the loss of normal everyday life, loss of time with friends and family members, loss of routines, or loss of plans. Many changes can be turned into good changes, but many will still feel sad.

Introduce your child to healthcare team members who provide psychosocial support, such as a psychologist, nurse, social worker and child-life specialist. Let members of the healthcare team know what you are sharing with your child and encourage your child to talk to them too. In addition to helping you explain the illness and its treatment to your child, they can help your child better understand his or her disease through medical play or other activities.

If your child shows strong feelings about the diagnosis, such as anger or sadness, let him or her know that it is normal to have these feelings and that it is okay to express them. Give your child an outlet to process his or her feelings, such as play or journaling.

Understand that, at times, your child may act as if there were nothing wrong. You may wonder if he or she understands what is happening. It is common for children to process information in small amounts. For some children, this is a way of coping that lets them go at their own pace.

You may need to have multiple conversations with young children. Children need time to absorb information and only take in so much information at one time. You may need to revisit the conversation after your child has had time to process what you talked about. It may be helpful to ask your child to repeat back information so you can correct any misunderstandings. As children grow older, they may need and want to know more about their illness and treatment.

Including Your Child in Discussions With the Healthcare Team. If your child would like to be included in meetings with the healthcare team, try to make every effort to do so. Allowing your child to participate will increase his or her sense of control and increase the opportunity to have his or her needs met. If your child would rather not be included in these discussions, then it is important to honor this request as well. Avoid discussing your child and the treatment plan in front of your child without including him or her in the conversation.

TIP:

For children of any age, if you notice troubling changes in mood or behavior, reach out to the healthcare team for help.

If there is information that you are not comfortable discussing in front of your child—for example, the long-term prognosis—then you can arrange to speak privately with the healthcare team.

Age-Appropriate Discussion. Keep the discussion age appropriate when you talk to your child about his or her diagnosis. Consider the following guidelines by age.

Baby/Toddler (0 to 3 Years)

- Children this young do not have an understanding of illness or cancer. However, they are aware of changes to routines and the feelings of people around them.
- Children in this age-group may be afraid of the medical staff and medical procedures.
- They may be afraid of abandonment or being left at the hospital. Offer physical and verbal reassurance.

Preschool/Kindergarten (4 to 6 Years)

- Children may have some understanding of an illness, such as a cold, but not grasp the implications of a serious illness.
- Children's primary focus will be the symptoms they are experiencing in any specific moment.
- Children in this age-group may be afraid of pain, so explain tests or treatments to them in advance.
- Assure your child that he or she did nothing wrong to cause the cancer.

Elementary/Middle School (7 to 12 Years)

- Children in this age-group may have a better understanding of serious illness, but not specifically cancer.
- They may have heard things about cancer at school, from friends, on TV or they may have found information online. Ask your child what he or she knows and correct any misunderstandings, especially those that cause distress.
- Explain tests, treatments, and other medical procedures in advance. Your child may be afraid of pain and resist some tests or procedures. Be honest. If a procedure might be painful, work with the healthcare team and decide how to explain what will be done to lessen pain and why the procedure is important.
- Talk to your child, in advance, about possible changes to his or her physical appearance.
- You may need to discuss fertility preservation with your child. Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, may be an option for children who have begun puberty. Fertility preservation needs to be done before treatment begins. Enlist members of the healthcare team to help with this sensitive discussion.
- You may see signs of regression in a child's behavior, such as thumb sucking, bed-wetting or tantrums.
- A child may use play to process the information, play-acting doctor/patient scenarios, for example.
- If the cancer treatment will result in any changes to the child's daily routine, explain the changes ahead of time so that the child knows what to expect.

High Schoolers/Teenagers (13 to 18 Years)

- Teenagers understand more about cancer and may want to know more. You may still need to correct any misinformation your teenager has heard about cancer from school, friends, TV, movies or has found online.
- Teenagers may want to participate in decisions about their treatment. Include them in discussions with members of the healthcare team, as appropriate.
- You may need to discuss fertility preservation with teenagers. Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, needs to be done before treatment begins. Enlist members of the healthcare team to help with this sensitive discussion.
- High schoolers and teenagers may also be very concerned about changes to their physical appearance, such as hair loss and losing or gaining weight, as well as worrying about how their peers will react to the changes.
- As teenagers struggle to find independence, a cancer diagnosis may feel like a setback that can lead to feelings of frustration and anger. They may try to test their boundaries or engage in risky behaviors, such as drinking, drug use, or sex.

Children’s Books About Cancer. You may find it helpful to use books and/or illustrations to help your child better understand the implications of cancer and cancer treatment. Ask a child-life specialist or other members of the healthcare team for recommendations. Here are some suggestions:

- *Pictures of My Journey—Activities for kids with cancer* from The Leukemia & Lymphoma Society (LLS)
 - An activity and coloring book for children with cancer in which Bailey, a young cancer patient, shares his experience with cancer treatment. Visit www.LLS.org/booklets to order or download for free.
- *The Stem Cell Transplant Coloring Book* from The Leukemia & Lymphoma Society (LLS)
 - A coloring book for children with blood cancer who are coping with having a stem cell transplant. Visit www.LLS.org/booklets to order or download for free.
- *Henry and the White Wolf* by Tim Karu and Tyler Karu
 - Geared to help children cope with the physical discomforts and fears of prolonged medical treatment, this story is an allegory about a sick hedgehog that is healed by the feared white wolf.
- *Samson’s Tale* by Carla Mooney and illustrated by Kathleen Spale
 - This book tells the story of a young boy with leukemia from his pet’s perspective. It chronicles the boy’s experience with chemotherapy and his illness.
- *Stevie’s New Blood* by Kathryn Ulberg Lilleby and illustrated by Chad Chronick
 - Stevie is undergoing a bone marrow transplant to treat his leukemia and his sister, Anna, is his donor. The story explains bone marrow and stem cell transplantation from a child’s point of view and can be adapted for children of various ages.



LLS Children's Coloring App. The free *LLS Coloring for KidsSM* app allows children to express their creativity and also offers activities to help them learn about blood cancer and its treatment. The app includes blank canvases, general coloring pages, and pages from LLS coloring books *Pictures of My Journey—Activities for kids with cancer* and *The Stem Cell Transplant Coloring Book*. This app can be used anywhere and may help children to pass time in waiting rooms or during treatment.

Additional features of the app include

- Custom colors
- Glitter and pattern tools
- Stickers
- Frames
- Resources for parents

Visit www.LLS.org/ColoringApp to learn more and download.

Questions for You to Ask Your Child. To guide conversations with your child, you may find it helpful to work through the following questions together (as age appropriate). You may also wish to revisit these questions as treatment progresses to check in with your child.

- What do you know about cancer and cancer treatment? Do you know anyone who has cancer? (Many children have experiences with older adults who have cancer. If your child has had such an encounter, this can be a helpful way to open a discussion; however, it is important to share with your child that childhood cancers are different than adult cancers. You may need to address concerns related to these differences. Let your child explain what he or she knows about cancer so you can correct any misinformation.)
- What do you know about your illness and treatment plan (medicine)? (If you explain new information about a procedure or treatment, ask your child to repeat the information back to you so you can correct any misunderstandings.)
- Is there a special toy or item that you would like to take with you to appointments? (Ask the healthcare team if you need to take any precautions with toys and items that you bring to appointments.)
- Is there anything you are worried or scared about? Will you let me know if you feel scared or worried?
- Do you have questions for your doctor? Would you like to ask these questions or do you want me to ask them for you? Would you like to talk to your doctor alone?
- Would you like to read or learn more about your cancer and treatment plan?
- Is there anyone you want to tell about your cancer diagnosis. Is there anyone you would like for me to tell for you?
- Are you okay with me sharing updates about your treatment or well-being with other family members and friends?
- Are there any things that you would like to do on your own? (Older children, especially teenagers, may wish to do some tasks on their own. As your child is able, encourage him or her to continue taking care of his or her hygiene and personal care or household chores on his or her own.)
- Is there anything that you need or want me to help you do?
- Would you like to talk to other children your age with a cancer diagnosis? (Ask members of the healthcare team if there is a children's support group in your area.)



Use **Worksheet 3: Questions for You to Ask Your Child** to revisit these questions.

Your Child's Wishes and Preferences for Medical Care. Although parents or legal guardians are ultimately responsible for making decisions about a child's medical care, it is best practice to take into account the child's wishes and preferences for medical care too. Discuss with your child what approach he or she prefers when it comes to medical care and include the members of the healthcare team in these discussions. Reach out to a social worker or child-life specialist to help facilitate these conversations.

Here are examples of the types of questions you may want to ask your child during these discussions:

- When members of the healthcare team come into the hospital room, do you want them to explain what they will do before they do it? (For example, taking vital signs or drawing blood)
- What do you want members of the healthcare team to call you? (For example, a nickname)
- Do you want to be asked before being touched by members of the healthcare team?
- Would you like the curtains around your bed to be drawn for privacy during examinations?
- Do you want a countdown before a needlestick?
- If given a choice, do you prefer liquid or pill medications?
- If something causes pain, what makes you feel better?

Asking your child about his or her wishes and preferences builds trust between you and your child and builds trust between your child and members of the healthcare team too. Your child will be more comfortable and feel a sense of control. You will be better able to advocate for your child's care when both you and your child are communicating with the healthcare team.

Discussion Guides. These resources can help guide your conversations with your child about his or her wishes and preferences for medical care. These resources were created for advance care planning, but these discussion guides are also helpful for any child who is facing a serious illness or prolonged treatment. They can provide ways for him or her to communicate his or her wishes and preferences for medical care to family members and to the healthcare team.



Discussion guides for you and your child include:

- *My Wishes* is a booklet written in everyday language (available for purchase at <https://fivewishes.org/shop/order/product/pediatric-my-wishes>) that helps children express how they want to be cared for when, or if, they become seriously ill. You can view a sample of the *My Wishes* document at the link.
- *Voicing My Choices* is a discussion guide (available for purchase at <https://fivewishes.org/shop/order/product/voicing-my-choices>) that empowers young people who are struggling with a serious illness to communicate with family members, friends and caregivers about the type of care that they want now and in the future.

Teaching Your Child to Navigate the Healthcare System. It is important for everyone (parents and children [as age appropriate]) to learn how to navigate the healthcare system and advocate for care. To be successful, a person needs to be able to

- Talk to healthcare professionals and ask questions
- Request written information about a diagnosis, treatment, or medication
- Know family and personal medical history
- Alert the healthcare team to any new or worsening signs and/or symptoms

- Schedule appointments
- Take an insurance card and list of all current medications to appointments
- Make appointments with new providers; fill out the paperwork ahead of the appointment, if possible or arrive early to fill out necessary paperwork
- Seek a second opinion or ask for a referral to a specialist, when needed
- Know how to access medical records
- Maintain recommended follow-up and disease screening schedules
- Stay up-to-date on recommended vaccinations
- Make sure that medications are taken as prescribed
- Check with members of the healthcare team before taking any new medications (including over-the-counter medications, vitamins and supplements)
- Be honest with the healthcare team about lifestyle including drug and alcohol use and sexual activity
- Understand health insurance coverage and medical costs
- File a claim with insurance and appeal an unapproved claim

Every child, depending on his or her age, can learn many of these skills. Allow your child to learn by participating in his or her own care, as age appropriate. For example, encourage him or her to ask members of the healthcare team questions. Teenagers may want to speak to members of the healthcare team in private to discuss matters they are not comfortable sharing in front of a parent, such as questions about sex, substance use or mental health. Some children may wish to administer their own medications. You can allow them to do so with your supervision. By learning and practicing, your child will develop the necessary skills and awareness to advocate for his or her own care in the future.

When Your Child Becomes a Legal Adult. If your child is a teenager, keep in mind that the day your child becomes a legal adult, all medical decisions will be made by him or her. Your young adult will be the person that members of the healthcare team will ask to make medical decisions and sign consent forms.

At that point, your young adult will also have to sign paperwork at the hospital or treatment center, giving the healthcare team permission to communicate with you, the parent, about his or her medical information. You will no longer be allowed to make these decisions.

