

# Children with Cancer

## A Guide for Parents





# Children with Cancer: A Guide for Parents

|                   |  |           |
|-------------------|--|-----------|
| <b>DIAGNOSIS</b>  | <b>Introduction .....</b>  | <b>1</b>  |
|                   | <b>Types of Childhood Cancer .....</b>                                     | <b>2</b>  |
|                   | <b>Diagnosing and Staging Cancer .....</b>                                 | <b>4</b>  |
|                   | <b>Talking With Your Child .....</b>                                       | <b>8</b>  |
| <b>TREATMENT</b>  | <b>Hospitals That Specialize in Treating Children With Cancer .....</b>    | <b>14</b> |
|                   | <b>Clinical Trials .....</b>   | <b>23</b> |
|                   | <b>Cancer Treatments and Side Effects .....</b>                            | <b>30</b> |
|                   | <b>Common Health Problems .....</b>  | <b>45</b> |
| <b>SUPPORT</b>    | <b>Finding Ways to Cope and Stay Strong .....</b>                          | <b>52</b> |
|                   | <b>Helping Your Child to Cope .....</b>                                    | <b>55</b> |
|                   | <b>Helping Brothers and Sisters .....</b>                                  | <b>60</b> |
|                   | <b>Getting Organized.....</b>  | <b>63</b> |
| <b>LIFE AFTER</b> | <b>Survivorship and Follow-up Care .....</b>                               | <b>66</b> |
|                   | <b>If Treatments Aren't Working .....</b>                                  | <b>72</b> |
|                   | <b>Looking Forward .....</b>   | <b>75</b> |
| <b>RESOURCES</b>  | <b>Practices That Help Children: Integrative Medicine Approaches .....</b> | <b>76</b> |
|                   | <b>Medical Tests and Procedures .....</b>                                  | <b>79</b> |



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Please note that for easy reading, we alternate between “he” and “she” to refer to a child with cancer.

# Introduction

*"When we first learned Lilly had leukemia, we walked around in a daze for weeks and barely slept. After the initial shock, we decided to learn all we could about this type of cancer. We also joined a support group at our hospital. Lilly is a fighter—it has been 5 years now and she is cancer free."*



Being told that your child has cancer is extremely difficult. Many parents say they felt overwhelmed and confused in the first days and weeks after their child's diagnosis. This guide has both medical information and coping advice that can help your child and your family.

Keep in mind:

- **You are not alone.** Your child's treatment team has many specialists who will care for the physical and emotional needs of your child. They will also help support your family during this difficult time.
- **More children than ever before survive childhood cancer.** Most parents have good reason to be hopeful that their child will get better.
- **Knowledge is power.** Many people and resources are available to help you learn about the type of cancer your child has, how it's treated, and what to expect.

This guide aims to give parents practical support that can help you find a doctor, talk with your child, help your family to cope, organize medical and insurance information, and learn about additional resources. It also includes information to help you learn more about specific types of childhood cancer, tests and procedures, treatments and clinical trials, health issues during treatment, steps to take if treatment isn't working, and survivorship.

This guide can also be [viewed online or printed](#).

# Types of Childhood Cancer



“Learn about the exact type of cancer your child has and how it’s treated. Some or even much of what you have heard about cancer will not apply to your child. We felt better when we knew how treatment could help our child.”

This section provides general information about childhood cancer. Here are some points to consider as you start to learn more:

**Cancer is a group of many related diseases, not one disease.** The word “cancer” is used to describe a group of diseases in which abnormal cells divide without control, invade nearby tissues, and spread to other parts of the body through the blood and lymph systems.

**Cancers in children are different from cancers in adults.** The parts of the body in which cancer occurs most often are different for children and adults. The most common childhood cancers are leukemia, brain and other central nervous system tumors, and lymphoma. Together, these cancers account for more than half of all cancers diagnosed in children but only a small percentage of the cancers diagnosed in adults.

**The causes of childhood cancer are not well understood.** Although a small number of cases of childhood cancer are due to **genetic** abnormalities, the causes of most childhood cancers are unknown.

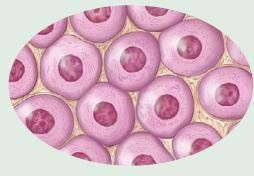
**Children of all ages, races, and economic backgrounds get cancer.**

**More children survive cancer now than ever before.** New and better treatments help many children with cancer. Today, more than 80 percent of children and adolescents (under the age of 20) who are diagnosed with cancer survive for at least 5 years after their diagnosis. However, survival rates for some childhood cancers are still low. Much of the improvement in childhood cancer survival rates is due to **clinical trials** that have taken place over the past four decades.

**Teams of specialists treat children with cancer.** These teams are most often found at university or children’s hospitals that are members of the Children’s Oncology Group.

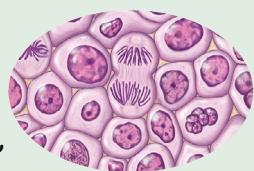
## More about cancer

Normal cells grow and divide in an orderly process. The body makes more cells only when it needs them. When normal cells grow old or get damaged, they die, and new normal cells take their place.



Normal cells

Abnormal (cancer) cells grow and divide in an uncontrolled fashion. For example, new cells form when the body doesn’t need them, and old or damaged cells don’t die when they should. Cancer cells can invade and damage nearby tissues and spread to other parts of the body. The spread of cancer from one part of the body to another is called **metastasis**.



Abnormal cells

# Childhood cancers

The most common childhood cancers include:

## Brain cancer

- Brain and spinal cord tumors begin in the tissues of the brain and spinal cord. The brain and spinal cord make up the central nervous system (CNS).

**Germ cell tumors** often begin in the testicles or ovaries, although they can form almost anywhere in the body. These types of tumors include:

- **extracranial germ cell tumors** (tumors form outside the brain)
- **central nervous system germ cell tumors**

**Leukemia** starts in the blood-forming tissue of the bone marrow. Types of leukemia include:

- acute lymphoblastic leukemia (ALL)
- acute myeloid leukemia (AML)

**Lymphoma** starts in the lymphatic system, which is part of the body's **immune system**. There are several types:

- Hodgkin lymphoma
- non-Hodgkin lymphoma

**Neuroblastoma** forms in nerve tissue in the neck, spinal cord, or adrenal gland.

**Sarcoma** is cancer that forms in the bone, muscle, or soft tissues. There are several types:

- **Ewing sarcoma** forms in the bone or soft tissues
- **osteosarcoma** forms in the bone
- **soft tissue sarcoma** forms in muscle, fat, fibrous tissue, blood vessels, or other supporting tissues of the body
- **rhabdomyosarcoma** is the most common type of soft tissue sarcoma in children, it forms in the muscle tissues

## Wilms tumor and other childhood kidney tumors

- Wilms tumor forms in the kidney.

## More types of childhood cancer

For detailed information about these and other childhood cancers see our [Pediatric Cancer Treatment Summaries \(PDQ®\)](#). Each summary includes information about signs of specific types of cancer, tests that may be used to make a diagnosis, and treatment choices.

## Related resources

- [Alphabetical List of Pediatric Cancer Treatment Summaries \(PDQ®\)](#)
- [Childhood Cancers](#)

# Diagnosing and Staging Cancer

This section explains how cancer is diagnosed in children. It will help you learn what tests are used to diagnose cancer and how staging systems, risk groups, and grades may be used to plan treatment for your child and to make a **prognosis**.

## Common symptoms

The early symptoms of childhood cancer are often similar to ones that are commonly seen in other illnesses. These symptoms may include fever, feeling tired, swollen glands, or weight loss. Others, such as bruising or tender joints or bones, may lead a parent to suspect an injury. When these signs and symptoms last or are severe, the doctor may order tests to check for cancer or other illnesses.

## Tests and procedures

The following tests and procedures are used to diagnose cancer in children. The type of test done depends on your child's symptoms, age, medical history, and the type of cancer doctors think it may be.

- A **physical examination** and **blood tests**
- **Scans** are imaging tests that make pictures of areas inside the body. Types of scans include **CT scan**, **MRI**, **PET scan**, **x-ray**, and **ultrasound**. A **radiologist** is a doctor who reviews the scans and sends a report of the findings to your child's doctor.
- A **biopsy** is a procedure in which samples of cells or tissue are removed and then checked to find out if cancer cells are present. When possible, biopsies should be done at a hospital that specializes in diagnosing cancer in children. A **pathologist** will study the cells or tissue samples taken during the biopsy and write a **pathology report**. This report describes what the cells or tissues look like when examined with a microscope and includes the diagnosis.

Learn more about these tests and procedures in the [Medical Tests and Procedures](#) section on page 79.

*“Before the biopsy, my daughter and I learned what was going to happen. We went to a large children’s hospital that had expertise in diagnosing and treating children with cancer.”*



## Questions to ask before a test or procedure

- Which test(s) or procedure(s) does my child need? What will the results tell us? \_\_\_\_\_  
\_\_\_\_\_
- Where should my child have this test or procedure done? \_\_\_\_\_  
\_\_\_\_\_
- How long will the test or procedure take? When will we know the results? \_\_\_\_\_  
\_\_\_\_\_
- What does my child need to do to get ready for the test or procedure? \_\_\_\_\_  
\_\_\_\_\_
- What happens during the test or procedure? Will my child be awake? \_\_\_\_\_  
\_\_\_\_\_
- Will my child feel discomfort or pain? Will medicine be given to help my child relax or sleep? \_\_\_\_\_  
\_\_\_\_\_
- What are the risks of this test or procedure? \_\_\_\_\_  
\_\_\_\_\_

## Questions to ask when you receive test results

- What did the test or procedure find? \_\_\_\_\_  
\_\_\_\_\_
- Will you explain what the **pathology report** says? \_\_\_\_\_  
\_\_\_\_\_
- What is my child's diagnosis? What type of cancer does my child have? \_\_\_\_\_  
\_\_\_\_\_
- What is the extent or severity (risk group, grade, or stage) of the cancer? \_\_\_\_\_  
\_\_\_\_\_
- Will more tests or procedures be needed? What will these tests or procedures tell us?  
Will they be painful? \_\_\_\_\_  
\_\_\_\_\_
- Who can give us a second opinion about the pathology report? \_\_\_\_\_  
\_\_\_\_\_

## Risk group, grade, or stage: Planning treatment



*"At first, everything was new and confusing. I was overwhelmed. Now I understand more, and if I don't understand something – I ask until I do."*

Depending on the type of cancer that your child has – the doctor will describe the cancer in terms of its **stage**, **grade**, or **risk group**. These systems, explained below, are used to describe how severe different types of cancer are and to plan the best treatment for each child. Get copies of all test results and reports used to make a diagnosis – as well as a written copy of your child's diagnosis.

- **Risk group:** For many childhood cancers, including leukemias, patients are assigned to a risk group (low, intermediate, or high) based on the child's age, clinical features of the disease, and the results of laboratory tests. For example, leukemia risk groups are based on the number of **white blood cells**, changes in **chromosomes**, and whether the leukemia has spread to the brain and spinal cord. Patients with lower-risk disease are more likely to have a good outcome and need less aggressive treatment than patients with high-risk disease.
- **Grade:** Other cancers, such as brain tumors, are often grouped and treated based on what cancer cells look like when examined with a microscope. **Low-grade** (also called well-differentiated) tumor cells look nearly normal under a microscope, grow slowly, and are less likely to spread throughout the body than **high-grade** (also called **undifferentiated** or poorly differentiated) cancer cells.
- **Stage:** Treatment for solid tumors (such as Wilms tumor, for example) may also be based on the stage of the cancer. Staging systems use numbers and letters to describe the extent and severity of the cancer.
  - Numbers: In stage I (also called stage 1) the tumor is usually small and has not yet spread to other parts of the body. In stage IV, (also called stage 4) the cancer is more advanced and has often spread (**metastasized**) from the place where it started to other organs or tissues in the body, such as to the bones.
  - Letters: The **TNM staging system** uses the letters T, N, and M to describe the stage. The letter **T** describes the size of the tumor, **N** describes whether or not cancer has spread to nearby lymph nodes, and **M** describes whether or not metastasis (the spread of cancer to other parts of the body) has occurred.

## Second opinion

Some parents decide to get a second opinion to confirm their child's diagnosis. Even highly experienced doctors may have different opinions. If you choose to get a second opinion, talk with the first doctor. You will need to get information such as slides, samples, or reports from the hospital where the **biopsy** was done to give to the second doctor.

It's common to get a second opinion and most doctors welcome another doctor's views. Some health care plans require a second opinion. Other health care plans will pay for a second opinion if you ask for one. If your plan does not cover a second opinion, you can still get one if you are willing to cover the cost.

## Prognosis

A **prognosis** is the chance that the cancer can be treated successfully and that your child will get better. It is based on information collected over many years from large numbers of people who were diagnosed with the same type of cancer. Factors that may affect your child's prognosis include the type of cancer your child has, how advanced the cancer is, your child's age, and how your child responds to treatment.

As you talk with your child's doctor about your child's prognosis, keep in mind that:

- Survival statistics may be based on all patients with a specific type of cancer – or only some of them. One statistic that is commonly used in making a prognosis is the **5-year survival rate**. This rate is the percentage of people diagnosed with a specific type of cancer who are still alive 5 years after they were diagnosed.
- Survival statistics use information collected from large groups of people who may have received different types of treatment.
- Since it takes several years to see the effect of newer and better treatments, these effects may not be reflected in current survival statistics.

Because statistics are based on large groups of people, they cannot be used to predict exactly what will happen to your child. Everyone is different. Treatments and how people respond to treatment can differ greatly.

## Related resources

- [Cancer Staging](#)
- [Pathology Reports](#)
- [Tumor Grade](#)
- [Understanding Cancer Prognosis](#)

# Talking With Your Child



*“My son was old enough and smart enough for me to level with him about everything. I learned as much as I could about the cancer he had, but mostly I did what parents do best—I loved and was always there for my child.”*

This section has advice to help you talk with your child. Begin with the knowledge that you know your child best. You know what makes your child laugh, and you know what upsets your child. Your child depends on you for helpful, accurate, and truthful information. Talk calmly and directly with your child during this frightening time.

Honesty builds trust. Tell your child about the illness and what to expect. This will help your child trust you and the health care team. Children who are not told what is happening or why are often fearful and may imagine the worst.

Work together with people on your child’s health care team, such as **social workers** and **child life specialists**. Social workers are professionals who talk with people and their families about emotional and physical needs and help to find them support services. Child life specialists are health care professionals who are trained in the **developmental** and **psychological** needs of children and who help children understand and cope with medical issues.

## Information for children of different ages

Your knowledge and insights about your child, combined with your health care team’s expertise, can help your child:

- learn about the cancer, how it will be treated, and what to expect during treatment
- manage and deal with painful treatments or procedures
- cope with feelings and get social support
- have some control over the situation
- know they are loved, supported, and surrounded by people who care about them

## If your child is less than 1 year old

Comfort your baby by holding and gently touching her. Skin to skin contact is ideal. Bring familiar items from home, such as toys or a blanket. Familiar sights and smells can help your baby feel more secure. Talk or sing to your child, since the sound of your voice is soothing. Try to keep up feeding and bedtime routines as much as possible.



*"I found that just humming to my baby and gently rubbing her feet kept her calm during blood draws."*

## If your child is 1 to 3 years old

Very young children understand things they can see and touch. They fear being away from their parents and want to know if something will hurt. Toddlers like to play, so find safe ways to let your child play. Toddlers also like to start making choices, so let your child choose a sticker or a flavor of medicine when possible. Prepare your child ahead of time if something will hurt. Not doing so may cause your child to become fearful and anxious.



*"Toys in the playroom at the hospital kept Riley busy while we waited to be seen by the doctor. We also brought a backpack filled with some of his favorite toys and his blanket."*

## If your child is 3 to 5 years old

To help your child understand his treatment better, ask the doctor if he can touch the models, machines, or supplies (tubes, bandages, or ports) ahead of time. If a test or treatment may hurt, prepare your child in advance. You can also distract your child and try to take her mind away from the pain by reading a story or giving her a stuffed animal to hold.



*"We found a picture book about the hospital. Jamie wanted us to read it all the time. We still have the book, even though she's completed treatment."*

## If your child is 6 to 12 years old

School-aged children understand that medicines and treatment help them get better. They are able to cooperate with treatment but want to know what to expect. Children this age often have many questions, so be ready to answer them or to find the answers together. Talk with your child's doctor or nurse for answers to difficult questions or situations. Relationships are important, so help your child to stay in touch with friends and family.



*"John just turned 11, and he is really interested in how treatment works. He's always asking questions. He tells his big brother not to worry—that he will be fine. His doctor says he will make a great doctor one day!"*

## If your child is a teenager

Teens often focus on how cancer changes their lives—their friendships, their appearance, and their activities. They may be scared and angry about how cancer has changed their life and isolated them from their friends. Friendships are very important at this age, so look for ways to help your teen stay connected to friends through texting, e-mails, online video chats, letters, pictures, and visits. Some teens use social media sites to stay connected to friends.

Your teen may feel that cancer has taken a lot of her freedom and privacy away. She may need to depend on you at a time when she is trying to become her own person. It will likely help to give your teen some of the space and freedom she had before treatment and encourage independence. Make sure your teen is included in treatment planning and other choices.

Some teens with cancer feel as if nothing bad could ever happen to them, and others have fears about death. Your teen may try to protect you and others they love by holding in their feelings. Don't assume you know what your teen is thinking. Take time to observe and listen. Many people, teens included, have trouble sharing their thoughts and feelings. Sometimes it may be easier for your teen to confide in a friend or a member of the health care team than in you.



*"Jackie is 14 and really social. She sees her friends between chemo treatment cycles. They do normal teen stuff—watch movies, play video games, and hang out. This weekend they made a poster using photos they've taken and pictures from magazines. We put it up on her wall. It was good to hear laughter coming from her bedroom again!"*

## Questions from parents

Although you want to be honest and helpful, you may not know what to say or when to say it. Your child will learn a lot from your tone of voice and facial expressions, so stay calm when you talk with your child. Work to be gentle, open, and honest. Being open and honest will allow your child to trust you and feel comfortable confiding in you. Use the suggestions below to get started. You may also want to refer to the [Information for children of different ages](#) section on page 8 to learn more.

*"On days when I couldn't be strong for myself,  
I was strong for my child."*



|   |  |
|---|--|
| <b>Who should tell my child?</b>            | Many parents receive their child's diagnosis from the doctor at the same time that their child learns of it. However, if you choose to be the one to tell your child, your child's doctor or nurse can help you decide what to say and how to answer your child's questions.   |
| <b>When should my child be told?</b>        | Your child should be told as soon as possible. This will help build trust between you and your child. It does not mean that your child needs to hear everything all at once.   |
| <b>What should I tell my child?</b>         | The information you share with your child depends on his age and what your child can understand. Children of all ages need clear, simple information that makes sense to them. As much as possible, help your child to know what to expect by using ideas and words that he understands. Tell your child how treatment will make him feel and when something will hurt. Explain that strong medicine and treatments have helped other children. Explain that treatments may cause changes in your child's schedule, and how your child may feel.   |
| <b>How much should I tell my child?</b>     | Help your child to understand the basic facts about the illness, the treatment, and what to expect. It may be hard for many children to process too many details or information given too far in advance. Start with small amounts of information that your child can understand. You can share more information over time if it seems as if your child will be able to understand and cope with the information.<br><br>Encourage your child to come to you with questions. Use your child's questions as a guide to understand what is on her mind. Children often use their imaginations to make up answers to unanswered questions and may fear the worst. Answering your child's questions and having honest, ongoing conversations can help your child. Telling untruths can cause your child to distrust you or people on their health care team. |
| <b>How might my child react?</b>            | Each child is different. Some worry. Others get upset or become quiet, afraid, or defiant. Some express their feelings in words, others in actions. Some children regress to behaviors they had when they were younger. These are normal reactions to changes in life as they know it. Their schedule, the way they look and feel, and their friendships may all be changing. Expect that some days will be rough, and others will be easier. Tell, and find ways to show, your child that you will always be there for her.   |
| <b>What can I do to help my child cope?</b> | Children take cues from their parents, so being calm and hopeful can help your child. Show your love. Think about how your child and family have handled difficult times in the past. Some children feel better after talking. Others prefer to draw, write, play games, or listen to music.   |

## Questions from children

*“Keep it honest. Keep it simple. Sounds easier than it actually is, but if you focus on these things you and your child will be OK.”*



Your child may wonder why he got sick and how long it will take to get better. If your child is older, he may have heard about cancer or had a grandparent who died from cancer. Many children ask what will happen during treatment and how they will feel. Your child’s social worker, child life specialist, nurse, and/or psychologist can help you come up with answers that will be most helpful to your child.

### What is cancer?

Your child will understand her cancer by relating it to what she already knows. So, begin by finding out what your child knows or may have heard about cancer. Then help your child be less fearful and understand what is happening.

When talking about cancer with your child, start with simple words and concepts. Young children may understand that they have a lump (**tumor**) that is making them sick or that their blood is not working the way it should. Older children may find the explanation of cancer cells in the [Types of Childhood Cancer](#) section on page 2 to be helpful. Tell older children the exact type of cancer they have, such as “**leukemia**” or “**Ewing sarcoma**,” for example. Use more medical words over time. For children of all ages, explain that cancer is not contagious—it’s not an illness children catch from someone or they can give to someone else.

### Why did I get cancer?

Some children think they did something bad or wrong to cause the cancer. Others wonder why they got sick. Tell your child that nothing he—or anyone else—did caused the cancer, and that doctors are working to learn more about what causes cancer in children.

**You may tell your child:** I don’t know. Not even doctors know exactly why one child gets cancer and another doesn’t. We do know that you didn’t do anything wrong, you didn’t catch it from someone, and you can’t give it to anyone.

**Will I get better?**

Being in the hospital or having many medical appointments can be scary for a child. Some children may know or have heard about a person who has died from cancer. Your child may wonder if she will get better.

**You may tell your child:** Cancer is a serious illness, and your doctors and nurses are giving you treatments that have helped other children. We are going to do whatever we can to help you get better. Let's talk with your doctor and nurse to learn more.

**How will I feel during treatment?**

Your child may wonder how he may feel during treatment. Children with cancer often see others who have lost their hair or are very sick. Talk with your child's nurse or social worker to learn how your child's treatment may affect how your child looks and feels.

**You may tell your child:** Even when two children have the same type of cancer, what happens to one child may not happen to the other one. Your doctors and I will talk with you and explain what we know and what to expect. We will all work together to help you feel as good as possible during treatment.

# Hospitals That Specialize in Treating Children With Cancer

*“We found a doctor who specializes in treating the type of cancer that our son has through the Children’s Oncology Group—a network of hospitals with amazing childhood cancer experts. Our son likes his doctor, and we trust her. He’s completed treatment and is doing well.”*



After learning that your child has cancer, you will need to decide where to have your child treated. Sometimes children who are diagnosed with cancer need to start treatment right away. However, when possible, it's often valuable to seek a second medical opinion. This section helps you learn about hospitals that specialize in treating children with cancer, how to get a second opinion, and tips for working with your child's health care team.

## Choosing where to have your child treated

Most children with cancer receive treatment at places that specialize in treating cancer in children—such as a children’s hospital, university medical center, or cancer center. Hospitals that have experts in treating children with cancer are usually member institutions of the **Children’s Oncology Group (COG)**. COG is the world’s largest organization devoted to clinical research to improve the care and treatment of children and adolescents with cancer.

### Children’s Oncology Group (COG) member institutions:

- treat more than 90 percent of the children and adolescents who are diagnosed with cancer each year in the United States
- have more than 8,000 physicians, nurses, and other experts in childhood cancer who work at more than 200 children’s hospitals, university medical centers, and cancer centers throughout the United States and Canada, and at a growing number of international sites
- participate in **clinical trials**, which are research studies that help doctors to develop better treatments for children with cancer

You can ask your child’s pediatrician or family doctor for a referral or view an online [directory of COG locations](#). Parents and/or health professionals can also call NCI’s Cancer Information Service (CIS) at 1-800-4-CANCER to find hospitals that specialize in treating children with cancer. You may find a hospital that is a COG member institution in the city where you live, or you may choose to travel, or even move for a short time, to another city while your child receives treatment.

# Getting a second opinion



*“I’d tell parents to have their child treated at a hospital that specializes in treating children with cancer—perhaps even the type of cancer their child has. Getting a second opinion helped us make the best decision. We decided to travel to a children’s hospital that’s far from our home and we’re glad we did.”*

After you talk with one doctor about your child’s diagnosis and treatment plan, you may choose to get another doctor’s opinion. This is called getting a second opinion. Most doctors will support and understand your interest in seeking a second opinion. Sometimes insurance companies require a second opinion. Your insurance company can also tell you what steps to take in order to get a second opinion.

## A second opinion is especially helpful when:

- the first opinion on the treatment plan comes from a doctor who doesn’t specialize in or treat many children with the type of cancer that your child has
- there are complicated medical decisions that need to be made
- there are different treatment options to choose from
- your child has a rare cancer

The second opinion should come from a **pediatric oncologist**, preferably one who treats children who have the type of cancer that your child has. This doctor will usually have the most experience with, and the most knowledge about, the latest treatments. For some types of childhood cancer, it may be important to seek a second opinion from a subspecialist, such as an oncologic **orthopedic surgeon**.

If you choose to seek a second opinion, you will need to get important medical test results and reports from the first doctor to share with the second doctor. The second doctor will examine your child and review the pathology report, slides, and scans before giving treatment recommendations. The second doctor may agree or disagree with the first doctor’s opinion. If the second opinion differs from the first opinion, both doctors should explain why their proposed approach is better and how it is supported by medical evidence, such as the results of clinical trials for this type of cancer.

Having a pediatric oncologist or other subspecialist review your child’s case can ensure that all aspects of care and treatment are considered. Often, the doctor who talks with you about the treatment plan will first review and discuss your child’s case with other doctors at the hospital (this is called a **tumor board review** or a **multidisciplinary opinion**), so that the treatment plan reflects a consensus of the best approach for your child from a team of doctors.

Places to go for help in finding a second opinion include:

- a hospital that is a member of the [Children's Oncology Group](#)
- the [Pediatric Oncology Branch at the NIH Clinical Center](#) (1-877-624-4878)

## Specialists who care for children with cancer



*"We got to know the people on our child's health care team. These specialists worked together to treat our child. In the beginning, we wrote down names and took pictures to help us keep track of them all. We also gave them a photo of our family."*

Many different specialists work together to treat children with cancer. Your child may see some of the specialists listed below. Use this list to keep track of names and contact information for the people on your child's team.

### Doctors who treat children with cancer include:

The attending physician is usually a **pediatric hematologist** or **pediatric oncologist**.

- Pediatric hematologist:** A doctor who treats cancers of the blood and related blood disorders in children.

Name and contact information: \_\_\_\_\_

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- Pediatric oncologist:** A doctor who treats children with cancer.

Name and contact information: \_\_\_\_\_

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### Other doctors your child may see include:

- Neurologist:** A doctor who diagnoses and treats problems of the nervous system.

Name and contact information: \_\_\_\_\_

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- Neuroradiologist:** A doctor who specializes in creating and interpreting pictures of the nervous system.

Name and contact information: \_\_\_\_\_

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- Neurosurgeon:** A doctor who specializes in surgery on the brain, spine, and other parts of the nervous system.

Name and contact information: \_\_\_\_\_

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- Orthopedic surgeon:** A doctor who specializes in diagnosing and treating injuries and diseases of the musculoskeletal system. This includes the bones, joints, tendons, ligaments, and muscles.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Pain specialists:** Experts who treat pain include anesthetists, neurologists, palliative care doctors and nurses, pharmacists, and psychologists, among others.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Palliative care specialists:** Specialists who provide palliative care include palliative medicine doctors, social workers, nurses, chaplains, and child life specialists, among others. Palliative care aims to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment, and related social and spiritual problems.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Pediatric neuro-oncologist:** A doctor who specializes in diagnosing and treating brain tumors and other tumors of the nervous system in children.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Pediatric psychiatrist:** A doctor who specializes in the prevention, diagnosis, and/or treatment of emotional and behavioral disorders in children.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Pediatric psychologist:** A specialist who talks with your child about feelings and emotions.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Radiation oncologist:** A doctor who specializes in using radiation to treat cancer.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Radiologist:** A doctor who creates and interprets pictures of areas inside the body.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Pediatric surgeon:** A doctor who specializes in operating on children. There are many subspecialty surgeons, such as orthopedic surgeons, for example.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

- Urologist:** A doctor who specializes in diseases of the urinary organs in females and the urinary and sex organs in males.

Name and contact information: \_\_\_\_\_  
\_\_\_\_\_

## Other specialists who help care for children with cancer include:

- Child-life specialist:** A health professional who is trained in the emotional and developmental needs of children.

Name and contact information: \_\_\_\_\_

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- Education coordinator:** A teacher at the hospital who helps your child with academic work and may also coordinate school work with your child's teachers.

Name and contact information: \_\_\_\_\_

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- Nurse practitioner** (also called an **advanced practice nurse**): A registered nurse who has additional education and training in how to diagnose and treat disease. **Pediatric nurse specialist:** A registered nurse with an advanced degree in nursing who specializes in the care of children. **Case management nurse:** A registered nurse with special training in how to plan, manage, and evaluate all aspects of patient care, especially for patients who receive treatment over a period of time.

Name and contact information: \_\_\_\_\_

---

- Physical therapist:** A health professional who helps your child to maintain and improve strength, joint alignment, balance, and endurance.

Name and contact information: \_\_\_\_\_

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- Physician assistant:** A health professional who is licensed to do certain medical procedures under the guidance of a doctor. A physician assistant may take medical histories, do physical examinations, and give injections, for example.

Name and contact information: \_\_\_\_\_

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- Registered dietitian:** A health professional with special training in the use of diet and nutrition who helps to improve the nutritional health of a patient.

Name and contact information: \_\_\_\_\_

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- Social worker:** A professional trained to talk with people and their families about emotional or physical needs, and to find them support services.

Name and contact information: \_\_\_\_\_

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- Spiritual leader, spiritual care worker, pastoral counselor, or religious leader:** A person who is trained to give spiritual advice and counseling.

Name and contact information: \_\_\_\_\_

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## Questions to ask when choosing a hospital

### About the hospital, doctor, and other members of the health care team

- Is this hospital a member of the **Children's Oncology Group (COG)**? \_\_\_\_\_  
\_\_\_\_\_
- How long have you been a board-certified pediatric oncologist? \_\_\_\_\_  
\_\_\_\_\_
- Are you the doctor who will treat and care for my child? Do you specialize in treating the type of cancer that my child has? \_\_\_\_\_  
\_\_\_\_\_
- Who are the other specialists that will be on my child's health care team? \_\_\_\_\_  
\_\_\_\_\_

### About the treatment plan

To learn more about treatments for your child, you may refer to the list of [Questions to ask about clinical trials](#) section on page 28 and the list of [Questions to ask about your child's cancer treatment](#) section on page 32.

### About support services for your child

- What specialists and services are available to help my child both physically and emotionally?  
\_\_\_\_\_
- How often will my child see these specialists?  
\_\_\_\_\_
- What counseling and coping services are available?  
\_\_\_\_\_
- What **integrative medicine** practices are offered? (See the [Practices That Help Children](#) section on page 76 for more information.)  
\_\_\_\_\_
- What **fertility preservation** procedures do you have available or recommend?  
\_\_\_\_\_
- What type of academic support would my child have access to at this hospital?  
\_\_\_\_\_
- What activities and facilities (such as an activity room or computer room) are available?  
\_\_\_\_\_

## About services for your family

- What programs and specialists do you have available to help parents and siblings cope? \_\_\_\_\_
  
- What are your visitor and overnight policies? \_\_\_\_\_
  
- What food services do you offer? \_\_\_\_\_
  
- Where do families stay? \_\_\_\_\_
  
- Would it be possible to talk with other parents who have had a child treated at this hospital? \_\_\_\_\_

## About practical and financial issues

- What types of insurance do you accept? \_\_\_\_\_
  
- What costs are covered? What costs do we need to pay up front or out-of-pocket? \_\_\_\_\_
  
- Do you offer counseling and support for financial and insurance-related issues? \_\_\_\_\_

## Working with your child's health care team



"We got to know our child's doctor. She was so open with us, took the time to explain things, and encouraged our son to ask questions so he understood everything too. We all worked together as a team, to help our son."

You and the people on your child's health care team will work together a great deal over the coming months. These suggestions can help you and your child to establish strong and effective relationships with the people on your child's health care team.

Suggestions to consider as you work with your child's health care team:

- **Build a strong partnership.** Give and expect to receive respect from the people on your child's health care team. Open and honest communication will also make it easier for you to ask questions, discuss options, and feel confident that your child is in good hands.
- **Advocate for your child.** You know your child best. When you notice that your child is having a difficult time, ask for extra help and support.
- **Take advantage of the many specialists who can help your child.** Your child's health care team has expertise in helping children during treatment for cancer. Work with them to help your child learn about cancer, how it will be treated, prepare for tests, manage side effects, and cope.
- **If you get information online, make sure the source is credible.** Although many parents look for information online, some are more comfortable getting information from the doctor and feel overwhelmed or fearful about doing their own research. What is important is to get accurate information that you can understand and use to make decisions to help your child.
  - Get recommendations for websites, books, and videos. Share what you find with your child's health care team to confirm these resources are relevant to your child.
  - Visit the hospital's library or resource center. Meet with a librarian or health educator.
- **Make sure you understand important information.** It can be overwhelming to take in and remember new medical information.
  - Speak up when something is confusing or unclear, especially when decisions need to be made.
  - Ask to see pictures or videos to help understand new medical information. Visuals are especially appreciated by children as well.
  - Take notes or ask if you can record a conversation with the doctor so you can listen to it again later.
  - Go with a family member or friend when you talk with your child's doctor. They can take notes, ask questions, and help you to remember important information.
- **Keep your child's pediatrician updated.** Ask for updates to be sent to your child's regular pediatrician.

# Practical steps to take for doctor visits

## Before (and between) visits:

- Prepare for each visit. Make notes to help you remember important information you want to discuss with your child's doctor. Use a notebook or computer to keep information organized and in one place.
- Write down questions and concerns as they arise. Make note of any changes you notice in your child—both physical and emotional.
- Bring your questions and notes with you to the doctor's visit. Put the most important questions first on the list.

## During the visit:

- Include your child in the conversation. Let your child talk and ask questions. If you or your child does not understand something, speak up.
- Take notes or ask to record the visit, so you can remember important information.
- Tell your child's doctor about all medical and emotional changes you notice in your child.
- Find out what urgent medical problems you should watch for. Know what problems can be managed at home and which require urgent medical care in an emergency room.
- Get the names and phone numbers of people on your child's health care team. Make sure you know who to call at all times, including nights and weekends.
- If you still have more questions, ask to schedule another visit or a follow-up call.

## After the visit:

- Call about any problems, concerns, or changes you notice between visits.
- Continue to track (using a notebook or computer) test results, medicines, and treatments your child receives.

## Related resources

- [Locations of Children's Oncology Group Hospitals \(COG\)](#)
- [How to Find a Doctor or Treatment Facility](#)
- [Cancer in Children and Adolescents](#)

# Clinical Trials

“Ask questions and learn about the best chance for curing the type of cancer your child has. It might be a clinical trial, or it might not be—but you won’t know unless you ask. We decided that a new treatment being given through a clinical trial was the best choice for our child.”



## Many children with cancer have treatment options, including standard medical care or treatment in a clinical trial.

- Standard medical care (also called **standard of care**) is treatment that experts agree is appropriate and accepted for a specific disease.
- **Clinical trials** (also called **clinical studies**) are a type of research study that test new medical approaches in people. Some cancer clinical trials compare a new treatment, or a new way of giving a standard treatment, with the standard treatment to see if it works better or has fewer side effects. Others determine the best amount of a drug to give.

**It is important to learn about all of the treatment options available to your child.** Most children with cancer receive treatment through participating in a clinical trial. The high clinical trial participation rate accounts for much of the progress in treating childhood cancers. In some cases, clinical trial results have led to treatments with fewer or reduced side effects. Other times a clinical trial may help doctors learn about the best dose of a medicine. Once a new treatment has proven safe and effective in a clinical trial, it may become the standard of care.



“I called 1-800-4-CANCER to get information about clinical trials that were open for the type of cancer my child has. This helped us talk with our child’s doctor to learn more.”

# Commonly asked questions

## What are clinical trials?

Clinical trials are a type of research study that test how well new medical approaches work in people. Clinical trials can test new ways to prevent, detect, diagnose, or treat a disease. This section focuses on clinical trials of treatments for children with cancer.

## How can clinical trials help children with cancer?

Several benefits of taking part in a cancer treatment clinical trial include:

- being among the first to receive a promising new treatment that may not be available outside of a clinical trial
- taking part in research that may help others who will need cancer treatment in the future
- receiving high-quality care, including close monitoring, from a health care team that is skilled in the latest practices of caring for cancer patients

## Are there possible risks in taking part in a clinical trial?

Possible risks and/or inconveniences from taking part in a cancer treatment clinical trial include:

- receiving a treatment that has unexpected side effects or may turn out to be no better, or even worse, than the standard treatment
- being required to make more visits to the doctor for tests and check-ups

## Who sponsors and approves clinical trials?

Many different organizations, including the National Cancer Institute (NCI), drug companies, universities, and medical institutions, sponsor cancer treatment clinical trials for children. Each **clinical trial sponsor** has procedures for approving the clinical trials that it supports. For example, the approval process for NCI-sponsored COG clinical trials includes review by childhood cancer experts to ensure that the treatments are appropriate and that the research questions are a high priority for the cancers being studied.

In addition to the sponsor's review and approval procedures, a group called an **institutional review board (IRB)** must also approve the detailed plan (**protocol**) for every clinical trial, before it can begin. IRBs, which include scientists, doctors, members of the clergy, and patient advocates, make sure that clinical trials are well designed, ethical, and legal. These review boards also monitor the safety and progress of the trials.

## Who pays for the cost of a clinical trial?

The two types of costs associated with a clinical trial are patient care costs and research costs. Patient care costs are expenses that are part of normal cancer care, such as doctors' fees, routine laboratory tests, and hospital stays, for example. These are usually covered by your insurance company. Research-related costs are items such as the drug(s) being studied, laboratory tests that are part of the research plan, and the research team's time. The clinical trial sponsor generally pays for these. Costs that may not be covered by either the insurance company or the sponsor include expenses for travel, hotel costs, and other related personal expenses, for example. Always check with your insurance company and the hospital/sponsor to find out which costs they cover and whether any costs will not be covered.

## How can my child get into a clinical trial?

To get into a clinical trial, children first need to be evaluated to see if they meet the requirements for trial participation as outlined in the study **protocol**. These requirements (also called **eligibility criteria**) may limit trial participation to people who have a specific type and stage of cancer or those in a certain age range. Many large children's hospitals and university hospitals participate in childhood cancer clinical trials. Ask your child's doctor about clinical trials that your child may be eligible to participate in.

## What is informed consent?

**Informed consent** is the process by which you will be given a detailed explanation about a clinical trial to help you decide if you want your child to participate. This process is carefully designed to protect the rights, safety, and privacy of children participating in clinical trials. As part of the informed consent process, the doctors and nurses on the research team will answer all of your questions about the trial.

The informed consent document includes information about:

- the name and purpose of the clinical trial
- the tests and procedures required by the clinical trial protocol
- the type of treatment received in the clinical trial (including when and for how long treatment will be given) and how it compares to the current standard treatment
- the possible benefits and risks of participating in the clinical trial
- any new information about the trial that might affect the decision to join or continue in the trial
- other treatments that are available
- your rights, such as the right to decide whether or not to have your child participate, as well as your right to withdraw your child from the trial at any time
- key contact information, including the names of the person in charge of the clinical trial (the **principal investigator**, or PI) and others on the research team

If you choose to have your child participate in a clinical trial, you will be given an informed consent form, which includes written details about the information that was discussed with you and describes the privacy of your child's medical records. You will have to sign this form to show that you agree to have your child take part in the clinical trial. Your child's doctor will also sign this form. However, the informed consent form is not a contract and you may withdraw your child from the clinical trial at any time.

## What is the assent process?

Your child will also be given information about the clinical trial and what to expect during treatment in a process called the **assent process**. Like the informed consent process, the aim of the assent process is an ongoing interactive conversation between the research team and the child. Although formal agreement, or consent, for a child's participation in a clinical trial comes from the parent(s) rather than the child, the child's agreement to participate (assent) may also be required.

During the assent process, your child will be given age-appropriate information about the purpose of the trial and what procedures they will undergo. The information will be given in a variety of ways depending on the child's age, including written forms, conversations, question-and-answer sessions, online videos, diagrams, and drawings.

It is important to understand and carefully consider all of the treatment options available for your child. Getting your questions answered can bring you to a place of understanding where you can make the best decision for your child. The list of [Questions to ask about clinical trials](#) section on page 28 may be helpful.

## Clinical trial phases

Clinical research is conducted in a series of steps, called **phases**. Each phase aims to answer specific medical questions. During early phase clinical trials, doctors learn about the safety, side effects, and best dose of a new treatment for a specific type of cancer. In later trials, doctors study whether the treatment works better than the current standard therapy and the long-term safety and effectiveness of a treatment.

### Phase I: Is the treatment safe?

Phase I clinical trials ask:

- What is the dose, or amount, of a treatment that can be given safely?
- What is the best way to give this treatment? For example, should it be given by mouth or by injection into a vein?
- What are the side effects?



*"Gaby's doctor helped us find a clinical trial that was testing a new drug. We believe this is her best chance. It's also a way to help doctors learn more and to help other children. Standard treatment was not working for our daughter."*

People who participate in a phase I trial often have advanced cancer for which the current standard treatment has not worked or for which there is no current standard treatment. If a phase I clinical trial shows that a treatment can be given safely to people, the best dose identified in the trial will be used in phase II trials of the treatment.

## Phase II: How does this treatment affect the cancer and the body?



*"We decided to enter our daughter in a phase II clinical trial with the hope that this treatment would shrink the tumor. Our doctor explained that a phase I clinical trial had already determined what amount of the drug should be given."*

Phase II clinical trials ask:

- Does this treatment have an effect in people with a certain type of cancer?
- What are the side effects of the treatment?

Phase II clinical trials use the dose that was found to be best in phase I trials. Phase II clinical trials continue to examine the safety and monitor the side effects of this new treatment. They also look for evidence that the treatment may affect the cancer, but a phase II trial cannot show for certain that a new drug is effective.

## Phase III trials: How does this treatment compare with the standard treatment?

*"Noelle's doctor thought that treatment in this phase III clinical trial was as good as, and perhaps better than, the standard treatment. We had to travel to a hospital that is further from our home, but we are glad to have found a hospital that gave us hope—and a doctor that our daughter formed a close relationship with."*



Phase III clinical trials ask:

- How does a new treatment, or a change to an existing treatment, compare with the current standard treatment?

Patients in a phase III trial are randomly assigned (assigned by chance) to a **control group** or an **intervention group**. People who are assigned to the control group receive the usual or standard treatment for their type of cancer. People who are assigned to the intervention group receive the treatment that is being tested in the clinical trial. Random assignment helps prevent unintended biases that could influence the results of the study, such as assigning sicker patients to the control group. Patients in both groups are monitored carefully during treatment and often for many months after treatment.

In some clinical trials, both the patients and doctors know which group the patient is. In other clinical trials, neither the patient nor the doctors knows which group the patient is in and which treatment the patient is receiving. The latter type of study—called a double-blind randomized clinical trial—is considered the gold standard of scientific evidence for a new treatment because the study design minimizes the possibility of the results being due to unintended biases. If the experimental treatment in a phase III clinical trial works better and/or is safer than the current standard treatment, it will likely become the new standard treatment.

## Related resources

- [Clinical Trials Information for Patients and Caregivers](#)
- [Children and Clinical Studies](#)
- [Children's Assent](#)
- [NIH Clinical Research Trials and You](#)

## Questions to ask about clinical trials

### About your child's treatment choices

- What are all of my child's treatment options? \_\_\_\_\_  
\_\_\_\_\_
- What is the current standard treatment for the type of cancer that my child has? \_\_\_\_\_  
\_\_\_\_\_
- What treatment clinical trials are open to children with this type of cancer? \_\_\_\_\_  
\_\_\_\_\_
- Which treatment would you recommend for my child? Why? \_\_\_\_\_  
\_\_\_\_\_
- At what hospitals is this clinical trial available? \_\_\_\_\_  
\_\_\_\_\_

## About a specific treatment clinical trial

- What is the goal of this clinical trial? \_\_\_\_\_  
\_\_\_\_\_
- How many children are currently taking part in this clinical trial? \_\_\_\_\_  
\_\_\_\_\_
- When did the clinical trial start? How long will it last? \_\_\_\_\_  
\_\_\_\_\_
- What type of treatment(s) would my child receive in the clinical trial? \_\_\_\_\_  
\_\_\_\_\_
- How does the treatment in this clinical trial compare with the current standard treatment?  
\_\_\_\_\_
- What doctors and specialists will my child see? Who will be responsible for my child's care?  
\_\_\_\_\_
- What tests will my child receive? How often? \_\_\_\_\_  
\_\_\_\_\_
- How might treatment in this clinical trial affect my child's day-to-day life and activities?  
\_\_\_\_\_
- What short- and long-term side effects might my child have? \_\_\_\_\_  
\_\_\_\_\_
- How long will treatment last? \_\_\_\_\_  
\_\_\_\_\_
- If my child takes part in this clinical trial, how will it affect the choice of future treatments?  
\_\_\_\_\_
- For what reasons would the clinical trial be stopped? \_\_\_\_\_  
\_\_\_\_\_
- May I talk with other parents who have a child in this clinical trial? \_\_\_\_\_  
\_\_\_\_\_

## About financial costs

- Who is sponsoring this clinical trial? \_\_\_\_\_  
\_\_\_\_\_
- What costs does the sponsor of the clinical trial cover? \_\_\_\_\_  
\_\_\_\_\_
- What costs does my health insurance policy cover? What costs do I pay for? \_\_\_\_\_  
\_\_\_\_\_

# Cancer Treatments and Side Effects



*"Our daughter's oncologist took the time to go over her treatment plan with us. He answered all of our questions and helped her know what to expect during treatment. We know our daughter is in skilled and caring hands. This gives us hope."*

Today cancer treatments are helping children to live longer and healthier lives than ever before. This section has information about treatment plans, side effects, and [Questions to ask about your child's cancer treatment](#) section on page 32.

Information is given in the following pages about these treatments:

- [Chemotherapy](#) information on page 34
- [Radiation therapy](#) information on page 38
- [Bone marrow transplantation and peripheral blood stem cell transplantation](#) information on page 40
- [Surgery](#) information on page 42
- [Immunotherapy](#) information on page 43
- [Targeted cancer therapies](#) information on page 44

## Treatment plan

The type of treatment children receive depends upon the type of cancer they have and how advanced the cancer is. Your child's age and other existing health conditions are also factors. Your child's doctor will go over the details of your child's treatment plan to help you and your child understand it. Often, pictures, videos, or drawings are used to explain how treatment works and what to expect.

You will receive a written copy of your child's treatment plan with information about:

- the goal of treatment and the type of treatment your child will get
- how often your child will get treatment
- how long treatment will last
- procedures and tests your child will have before, during, and after treatment
- possible **side effects** of treatment
- contact information for key medical people on your child's health care team

## Side effects

Your child's health care team will talk with you and your child about specific side effects your child may have, and how they will be managed. Side effects are health problems that happen when treatment harms healthy tissues or organs. Some treatments cause minimal side effects. Others can have serious side effects. Treatment is planned so your child has as few side effects as possible. Side effects can vary from child to child, even among those receiving the same treatment. Not every child gets every possible side effect of a particular treatment, and some children get few side effects.

## About fertility preservation

Ask your child's doctor whether treatment might affect your child's ability to have children in the future. If your child's doctor says that it might, then it is a good idea to talk with a fertility preservation specialist before treatment starts. Keep in mind that delaying treatment to address fertility options may not always be recommended. Nevertheless, it is important to talk with your child's doctor about the effect that treatment might have on your child's fertility before treatment begins.

Your child's age and sex will determine which procedures can be used for **fertility preservation**. Some of the treatment methods listed below are experimental and still being tested in clinical trials.

**Fertility preservation methods for girls** include shielding the ovaries during radiation therapy. For girls who have gone through puberty, eggs can be frozen (**egg cryopreservation**) before treatment. For girls who have not gone through puberty, the possibility of freezing ovarian tissue (**ovarian tissue cryopreservation**) before treatment is being studied in clinical trials.

**Fertility preservation methods for boys** include shielding the testicles during radiation therapy, **sperm banking** for boys who have reached puberty, and testicular sperm extraction and testicular tissue **cryopreservation** for boys who have not reached puberty. Testicular sperm extraction and testicular tissue **cryopreservation** (also known as freezing) are being studied in clinical trials.

For more information about fertility preservation or to find a fertility preservation center near you call the FERTLINE at (1-866-708-3378) or visit [Oncofertility Consortium®](#).



*"Even though our daughter's fertility was far from our minds, the doctor talked with us about how treatment might affect her ability to become pregnant one day. I'm glad that the doctor talked with us."*

## Questions to ask about your child's cancer treatment

### About treatment for this type of cancer

- What treatment(s) are available for the type of cancer that my child has? \_\_\_\_\_  
\_\_\_\_\_
- What treatment(s) do you recommend for my child? Why? \_\_\_\_\_  
\_\_\_\_\_
- What is the goal of this treatment? \_\_\_\_\_  
\_\_\_\_\_
- How will the treatment be given? What happens during a treatment session? \_\_\_\_\_  
\_\_\_\_\_
- How does this treatment work? \_\_\_\_\_  
\_\_\_\_\_
- What are the risks of this treatment? \_\_\_\_\_  
\_\_\_\_\_
- What are the next steps if my child's cancer does not respond to this treatment? \_\_\_\_\_  
\_\_\_\_\_
- About what percentage of children receiving this treatment are helped by it? \_\_\_\_\_  
\_\_\_\_\_

### About the treatment schedule

- How often will my child receive treatment? How long will each treatment last? \_\_\_\_\_  
\_\_\_\_\_
- Where will treatment be given? For example, will my child receive in-patient or out-patient treatment? Will hospital stays be needed? \_\_\_\_\_  
\_\_\_\_\_
- How many treatments will my child receive? How long will the entire treatment plan last? \_\_\_\_\_  
\_\_\_\_\_

## About side effects and supportive services

- How do children who go through this type of treatment feel—both physically and emotionally? \_\_\_\_\_
- What supportive care and complementary practices (such as music therapy, acupuncture, physical therapy, and guided imagery) are available to help my child feel better? \_\_\_\_\_
- What side effects may happen during treatment? How long will these side effects last? \_\_\_\_\_
- How will the health care team work to reduce these side effects? What can I do to help my child feel better? \_\_\_\_\_
- What permanent or lasting side effects might my child have after treatment is completed? \_\_\_\_\_
- Will my child's fertility be affected? What are the options to preserve my child's fertility? \_\_\_\_\_

## About making a decision

- When do we need to choose a type of treatment? \_\_\_\_\_
- When does my child need to start treatment? \_\_\_\_\_
- What procedures should my child have before starting treatment, for example, should my child have a dental check-up? Should my child and others in the family receive or avoid any vaccines? \_\_\_\_\_

## Related resources

- [Pediatric Cancer Treatment Summaries \(PDQ®\)](#)
- [Preserving Fertility in Children with Cancer \(ASCO\)](#)
- [Oncofertility Consortium®](#)
- [Side Effects](#)

# Chemotherapy



*“Our daughter’s nurse helped her through chemotherapy—telling her what to expect, and helping her smile.”*

## How chemotherapy works

**Chemotherapy** is treatment with drugs to stop or slow the growth of cancer cells. Chemotherapy works by destroying cells that are in the process of dividing. Most cancer cells divide rapidly, so they are the cells that are most likely to be destroyed by chemotherapy. However, some types of healthy cells also divide rapidly, which means that they can be destroyed by chemotherapy as well. Most chemotherapy drugs travel through the bloodstream, so they will eventually reach cells all over the body.

## How chemotherapy is given

The most common ways that chemotherapy is given are:

- through an **IV** (intravenous) line into a vein
- as a pill, capsule, or liquid that is swallowed (**oral chemotherapy**)

Chemotherapy may also be given:

- as a shot (**injection**) into a muscle or another part of the body or under the skin
- as a cream that is rubbed into the skin (**topical chemotherapy**)

Chemotherapy is given in **cycles**. A cycle is a period of treatment followed by a period of rest (no treatment). The rest period gives your child’s body a chance to build new healthy cells. For example, your child may get chemotherapy for 5 days in a row, followed by no chemotherapy for 10 days (that would be one cycle).

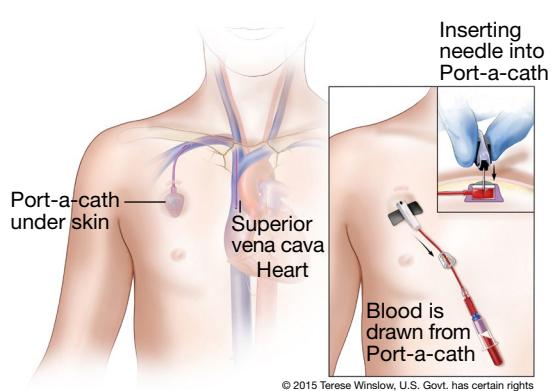
## More about intravenous chemotherapy

If your child is receiving chemotherapy through an IV line, then she will most likely have a catheter inserted into her body. A catheter is a thin, flexible tube that is used to give chemotherapy and other drugs, blood transfusions, and intravenous fluids and to take blood samples.

Types of **catheters** include:

- **Port-a-cath (port or subcutaneous implantable port).**

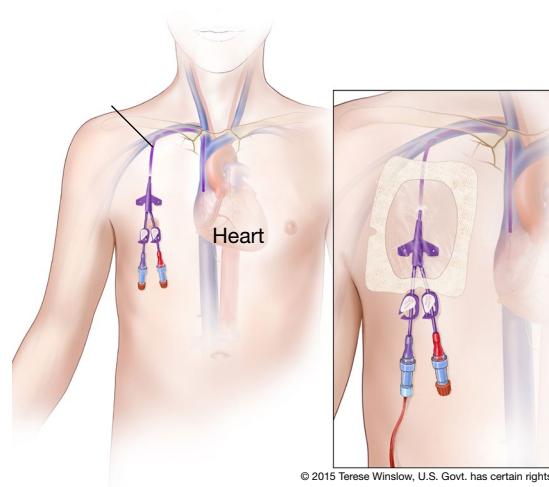
This type of catheter is a small, round disc made of plastic or metal with a silicone center. It is inserted under the skin on your child's chest during surgery. Your child may be given **general anesthesia** or placed under conscious sedation during this procedure. The port is connected by a catheter to a large vein in your child's chest. Chemotherapy is given through a needle that is inserted through the skin into the port. A numbing cream may be applied to the skin first. The needle is removed after the drugs are given. This type of catheter is completely inside your child's body, so it doesn't require any special care when your child is bathing. It can be left in for a long time, and your child has a lower chance of developing infections and blood clots with a port than with other types of catheters.



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- **Central venous catheter (tunneled catheter).**

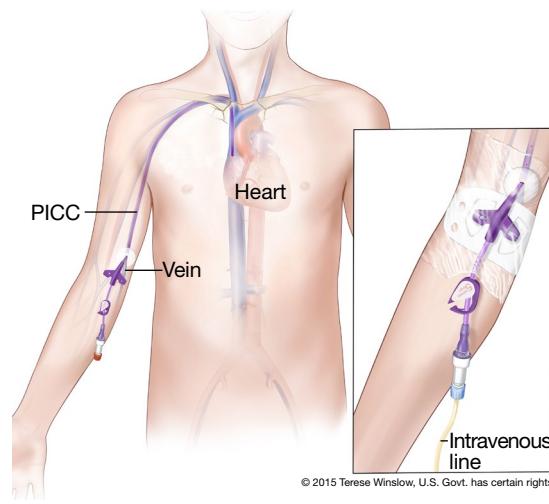
This type of catheter is a thin, flexible tube that is inserted through an incision in your child's chest during surgery and then threaded (tunneled) under the skin into a large vein near the heart or into the right atrium of the heart. The part of the catheter that is outside the body is taped to the chest and is used to give chemotherapy, so no needle sticks are needed. This type of catheter can be left in place for a long period of time. It needs to be cleaned (flushed) every day. Care needs to be taken so it does not get pulled out or wet. There is a small chance of infection and blood clots with this type of catheter.



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- **Peripherally inserted central catheter (PICC).**

This type of catheter is a thin, flexible tube that is inserted into a vein in the upper arm and guided into a large vein near the heart. This type of catheter can be inserted by a nurse and does not require surgery. The part of the catheter that is outside the body is taped to the skin on the arm and is used to give chemotherapy. This type of catheter avoids the need for repeated needle sticks and can stay in place for a long time. It needs to be cleaned (flushed) every day. Care needs to be taken so it does not get pulled out or wet. There is a small chance of infection and blood clots with this type of catheter.



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Catheters may be used for chemotherapy, as well as to give other medicine and for blood draws and **blood transfusions**.

## Side effects of chemotherapy

Chemotherapy destroys cells that grow and divide quickly. Cancer cells grow and divide quickly, but so do some healthy cells, such as cells that line the mouth and stomach and cells that make hair grow. Sometimes chemotherapy can slow or destroy cells in the bone marrow that make blood cells. Damage to these healthy cells causes **side effects**. Side effects differ greatly, depending upon the type of chemotherapy drug that your child is receiving.

- Common side effects of chemotherapy may include fatigue, nausea, diarrhea, mouth sores, hair loss, anemia, and increased risk of infection. You may find the practical tips in the [Chemotherapy Side Effects Series](#) helpful as you talk with your child's nurse to learn more.
- **Late effects** are problems that may happen months or years after treatment. You may want to ask your child's doctor about possible late side effects for the type of treatment that your child is receiving. You can learn more in the [Long-term and late effects](#) section on page 68.

## Special precautions you may need to take



*"John is getting a type of chemotherapy that made it very important to take certain safety precautions at home. Our child's nurse went over these instructions, such as wearing gloves at certain times and washing soiled sheets separately. Make sure you understand the instructions from your nurse and keep them handy."*

Many chemotherapy drugs are harmful to healthy people. You may need to take precautions if you are giving your child chemotherapy at home. Talk with your child's doctor about these and other precautions you may need to take.

- Take care not to touch:
  - oral chemotherapy drugs (such as pills, capsules, or liquids)
  - body fluids (such as vomit, urine, stools, or blood) from your child
  - items that are soiled with chemotherapy drugs or with body fluids, such as clothes or sheets
- Wear gloves if you are in contact with soiled items or body fluids.
- Wash soiled items (such as the countertop, bedpan, or bucket) with soap and hot water.
- Wash soiled items apart from the rest of the laundry. If you cannot wash soiled items right away, put them in a sealed plastic bag. Wash soiled laundry on the hot water cycle of the washing machine. Run the load twice.
- Double bag all soiled disposable items, such as used gloves. Ask your child's nurse how to dispose of soiled items. You may need to put them into special waste bags or containers marked "hazardous" and bring them back to the hospital for disposal.

## Questions to ask about safety precautions

### About taking necessary precautions to stay safe

- What special care and precautions should I take when caring for my child? \_\_\_\_\_  
\_\_\_\_\_
- What should I avoid touching or coming into contact with? For how long? \_\_\_\_\_  
\_\_\_\_\_
- How should I dispose of soiled items? \_\_\_\_\_  
\_\_\_\_\_
- What should I do if I touch soiled items or body fluids? \_\_\_\_\_  
\_\_\_\_\_
- What other problems or accidents should I call you about? \_\_\_\_\_  
\_\_\_\_\_

### About preparing oral chemotherapy

- Where should I keep and store the oral chemotherapy drugs? \_\_\_\_\_  
\_\_\_\_\_
- Should I wear a mask and/or gloves when handling these drugs? \_\_\_\_\_  
\_\_\_\_\_
- How often do I give these drugs to my child? What should I do if my child vomits? \_\_\_\_\_  
\_\_\_\_\_
- Should the drug be taken with or without food? \_\_\_\_\_  
\_\_\_\_\_
- Should pills be swallowed whole or can they be crushed? If the pill can be crushed, what should I use to crush it? \_\_\_\_\_  
\_\_\_\_\_
- How should I clean utensils, countertops, and other items used? \_\_\_\_\_  
\_\_\_\_\_
- What other precautions should I take? \_\_\_\_\_  
\_\_\_\_\_

## Related resources

- [Chemo, Craziness, and Comfort, My Book about Childhood Cancer](#) (ACCO)
- [Chemotherapy](#)
- [Side Effects](#)

# Radiation therapy



“Our child is such a curious kid. He always has questions. He wants to know ‘What’s going to happen today?’ and ‘How does it work?’ Talking with his child life specialist has helped a lot. So has reading together about how treatment works.”

## How radiation therapy works

**Radiation therapy** uses high-energy radiation to destroy cancer cells and shrink tumors. **External-beam radiation therapy** is the most common type of radiation therapy used to treat cancer in children. Other types include **internal radiation therapy** and **systemic radiation therapy**.

## How radiation therapy is given

- **External-beam radiation therapy** uses a machine that aims radiation at the cancer. Lead shields protect the parts of your child’s body that are not receiving radiation. Young children may be given medicine that helps them relax, stay still, or sleep during treatment. The machine that delivers the radiation is large and noisy, and it will rotate around, but will not touch, your child. This type of radiation is usually given every day for several weeks. Although each treatment session may last from 30 minutes to 1 hour, most of that time is spent getting your child in the correct position. Your child will most likely receive radiation for only 1 to 5 minutes during each visit.
- **Internal radiation therapy (brachytherapy)** uses a radiation source that is sealed in seeds, ribbons, or wires. The radiation source is placed inside the body near the cancer cells and may be left in place for minutes, hours, or days, depending upon the type of brachytherapy. Sometimes, the radiation source is left inside the body permanently, even after it is no longer giving off any radiation.
- **Systemic radiation therapy** is a type of radiation therapy in which a radioactive substance is swallowed or injected into the body and travels through the blood to destroy cancer cells. One example is radioactive iodine, which is used to treat some types of **thyroid cancer**.

## Side effects of radiation therapy

Radiation therapy can harm healthy cells as well as cancer cells. Damage to healthy cells causes side effects. Side effects depend on the part of the body receiving radiation as well as the dose of radiation. Talk with your child's doctor to learn what side effects your child may have, and learn how they will be managed.

- Common side effects of radiation treatment include skin irritation and fatigue. You may find the practical tips in the [Radiation Therapy Side Effects Series](#) helpful as you talk with your child's nurse to learn more about what side effects your child may have.
- **Late effects** are problems that may happen months or years after treatment. You may want to ask your child's doctor about possible late side effects for the type of treatment that your child is receiving. You can learn more in the [Long-term and late effects](#) section on page 68.

## Getting ready for external beam radiation therapy

Before receiving external beam radiation therapy, your child will have a treatment planning session (called a **simulation**) in which:

- detailed scans are taken of the tumor and the area of normal tissue around it
- small marks, often dots of ink, are put on the skin to show where to aim the radiation
- if needed, a body mold or mask is made to help your child stay in the exact same position during each treatment

## Related resources

- [Radiation Therapy](#)
- [Side Effects](#)

# Bone marrow transplantation (BMT) and peripheral blood stem cell transplantation (PBSCT)



*"Our child's nurse met with our daughter to help her learn what to expect and answer questions she had. It was very reassuring."*

## How BMT and PBSCT work

**Bone marrow transplantation** (BMT) and **peripheral blood stem cell transplantation** (PBSCT) are procedures that restore **blood stem cells** (also called **hematopoietic stem cells**) that are destroyed by the high doses of chemotherapy and/or radiation therapy used to treat children with certain cancers. Blood-forming stem cells are important because they make white blood cells that fight germs, red blood cells that carry oxygen to the body's tissues, and platelets that help blood to clot.

Most blood-forming stem cells are found in the **bone marrow**. Some are found in the blood circulating throughout the body (**peripheral blood**); they are also present in **umbilical cord blood**. Cells from any of these sources can be used in transplants. During a transplant, your child is given healthy blood-forming stem cells. These cells travel to the bone marrow, where they begin to make healthy blood cells.

## Types of stem cell transplants

- **Autologous** transplants use your child's own blood-forming stem cells. This type of transplant is used when there are enough healthy stem cells to collect before treatment. Any cancer cells are removed.
- **Syngeneic** transplants use stem cells from your child's identical twin, if there is one.
- **Allogeneic** transplants use stem cells from a biological sister, brother, parent, or other family member or from an unrelated **donor** whose stem cells match your child's stem cells as closely as possible.

## Finding a matched donor



*"Our daughter was a match for her sister. We knew of other children and teens who found a donor match through the [National Marrow Donor Program®](#)."*

Each person has a unique set of **proteins** on the surface of their cells. These proteins are called **human leukocyte antigens (HLA)**. The ideal donor for your child is one with the greatest number of matching HLA antigens. Having a well-matched donor lowers the risk of complications, such as

**graft-versus-host disease (GVHD)**, and increases the chance that your child's body will accept the donor's stem cells. Your child's biological siblings are more likely than an unrelated person to be a well-matched donor.

## About the transplant

Your child will receive stem cells through a catheter, just like a blood transfusion. This can take 1 to 5 hours.

Most children stay in the hospital for a period of time after the transplant to give the body time to create enough new white blood cells to fight infection. During this time, your child will be monitored closely and protected from germs. She will get frequent blood tests to make sure that new blood cells are being made and that the cancer has not come back.

Your child may also have a **bone marrow aspiration**. During this procedure, a small sample of bone marrow is removed through a needle and examined under a microscope to help doctors determine how well your child's bone marrow is working. Your child may also get transfusions of blood cells, **platelets**, and **antibiotics**.

After an **autologous** transplant, it may take your child's **immune system** several months to fully recover. After an **allogeneic** or **syngeneic** transplant, it may take 1 to 2 years for the immune system to return to normal.

## Side effects and risks of stem cell transplants

The likelihood of side effects is specific to each child's treatment. Your child's doctor will talk about which ones may apply to your child.

- Major risks include an increased susceptibility to infection and bleeding. Antibiotics may be needed to prevent or treat infection. Transfusions of platelets may be given to prevent bleeding and transfusions of red blood cells may be given to treat **anemia**.
- Short-term side effects may include appetite loss, fatigue, hair loss, mouth sores, nausea, vomiting, and skin reactions.
- **Graft-Versus-Host Disease (GVHD)** is a complication after an allogeneic transplant that can harm the skin, liver, and intestines. The white blood cells from the donor identify cells in the patient's body as foreign and attack them. Specific medicines are used to lower the risk of GVHD.
- **Late effects** are problems that may happen months or years after treatment. You may want to ask your child's doctor about possible late side effects for the type of treatment that your child is receiving. You can learn more in the [Long-term and late effects](#) section on page 68.

## Related resource

- [Blood-Forming Stem Cell Transplants](#)
- [Be The Match®](#), operated by the National Marrow Donor Program®

# Surgery

## How surgery is used to treat cancer

**Surgery** (also called an operation) is an essential part of treatment for many solid tumors. As much of the tumor as possible is removed. Your child may receive chemotherapy or radiation therapy before surgery, to shrink the tumor, or after surgery, to destroy any cancer cells that may remain. The type of surgery depends on the type of cancer your child has and where the tumor is located.

## Learn what to expect after surgery

After surgery, it is common to feel pain. Medicine is given to treat pain and to help your child be more comfortable. Side effects depend on the type of surgery and the size and location of the tumor. People on your child's health care team will prepare you and your child for the physical and emotional side effects of surgery. You and your child will also learn about types of **rehabilitation**, such as **physical therapy**, that may take place after surgery.

Talking with the parents of children who have had the same type of surgery that your child will have can be very informative and reassuring. This is especially true for surgeries that change your child's physical appearance, such as **amputation** or **limb-sparing surgeries**. Let your child's doctor know if you would like to talk with the parents of other children who have had a particular type of surgery. For example, it may also be possible for your child to talk with a child who has had an amputation, limb-sparing surgery, or other major surgery. Talking with a child who can now run, bike, swim, and do other physical activities can be reassuring.

## Types of surgery

- **Resection:** This is surgery to remove tissue or part or all of an organ. Often, the tissue around the tumor and sometimes nearby lymph nodes may also be removed during the operation.
- **Amputation:** An operation to remove a limb (arm or leg) that has cancer.
- **Limb-sparing surgery** (also called **limb-salvage surgery**): An operation to remove some types of tumors in a limb (such as an arm or leg) without removing the whole limb. Some of the bone and tissue around the tumor may also be removed, and the part of the limb that is removed may be replaced with an implant. This type of surgery helps to save the use and appearance of the limb. It is used to treat some cancers of the bone and soft tissue.
- **Craniotomy and resection:** An operation in which a piece of the skull is removed. It may be done to remove a brain tumor or abnormal brain tissue. During this surgery, an incision is made and a section of the skull is removed (called a craniotomy) to expose the brain. A **neurosurgeon** then removes as much of the tumor as possible (called **debulking**). The piece of skull that was removed is then put back in place.
- **Reconstructive surgery:** An operation to reshape or rebuild (reconstruct) a part of the body changed by previous surgery.

You can learn more about whether or not surgery will be used to treat the type of cancer that your child has by going to this [Alphabetical List of Pediatric Cancer Treatment Summaries PDQ®](#).

# Immunotherapy



*“Our son’s health was closely monitored during treatment. We were so glad to be able to get this treatment through a clinical trial.”*

## How immunotherapy works

**Immunotherapy** is a type of **biological therapy** that stimulates and strengthens the body’s **immune system**, so it can better fight cancer, infection, and other diseases. Immunotherapy may be used with other treatments, such as radiation therapy and chemotherapy. This type of treatment is being studied in clinical trials for specific types of cancer.

To understand immunotherapy, it helps to understand the immune system. This system is made up of a network of cells and organs that work together to defend the body against disease and infection. These include:

- white blood cells called **phagocytes, B lymphocytes** (antibody-producing cells), **T lymphocytes (helper T cells and cytotoxic T cells)**, and natural killer cells
- organs such as the **spleen, thymus, lymph nodes, tonsils, and bone marrow**

The immune system attacks things in the body that it recognizes as foreign, such as viruses and bacteria, as well as some damaged, diseased, or abnormal cells. This response is triggered when the immune system comes across a substance on the foreign invader (called an **antigen**) that it recognizes as “foreign.” However, some cancers have developed ways of evading detection by the immune system, or of suppressing the immune system, which is why immunotherapy is an important tool to fight cancer.

## How immunotherapy is given

Some types of immunotherapy are given as shots or pills. Others are given through an IV line.

## Side effects of immunotherapy

Side effects depend on the type of immunotherapy and vary from person to person. Your child’s doctor will talk with you about how to manage possible side effects of immunotherapy which may include:

- rashes or swelling where the treatment is injected
- flu-like symptoms (such as fever, chills, nausea, vomiting, loss of appetite, fatigue, bone pain, and muscle aches)
- allergic reactions, such as a rash, and wheezing or shortness of breath

## Related resources

- [Immunotherapy](#)
- [Cancer Immunotherapy in Children](#)

# Targeted cancer therapies



Researchers are working together to facilitate the discovery of molecular targets and to use those findings to improve treatment for children with cancer.

## How targeted cancer therapies work

Targeted cancer therapies (also called **molecularly targeted therapies**) are drugs or other substances that interfere with specific molecules involved in the growth of tumors. Sometimes this kind of treatment is referred to as **precision medicine**.

**Targeted therapies** work to:

- interfere with the way cancer cells respond to signals in their environment
- block the growth of blood vessels to the tumor, which prevents tumor growth
- promote a process of controlled cell death which cancer cells typically avoid
- stimulate the immune system to destroy specific cancer cells
- deliver toxic molecules to cancer cells, causing the cells to die

By focusing on molecular and cellular changes that are specific to cancer, targeted cancer therapies may be more effective than other types of treatment. Many targeted cancer therapies have been approved for the treatment of specific types of cancer. Others are being studied in clinical trials and many more are in earlier stages of development.

## How are targeted therapies given?

Some types of targeted therapy drugs are given intravenously (IV). Others are given as a pill that your child will take by mouth and swallow.

## Side effects of targeted therapy

The side effects of targeted therapy, for the most part, differ from those of standard chemotherapy and some can be substantial. Side effects are based on the specific targeted therapy drug that your child is receiving. Talk with your child's doctor about specific side effects and how they will be managed.

## Related resources

- [Targeted Cancer Therapies](#)
- [TARGET: Therapeutically Applicable Research to Generate Effective Treatments](#)
- [TARGET Initiative Leading the Way to New and Exciting Discoveries in Childhood Cancers](#)

# Common Health Problems

During treatment, your child's health care team will provide a type of care called **supportive care** or **symptom management**. This care helps to prevent or manage health problems caused by the cancer and its treatment, such as infection, stress, nutritional problems, pain, and changes to your child's immunization schedule. The following pages have tips to help with each of these health problems.

## Infection

*"David was great about washing his hands. The nurse said this was the most important step he and our family could take to prevent infection."*



**Infection** happens when germs invade and grow in the body. Children being treated for cancer are often at increased risk of infection. Some cancers and some types of treatment make it harder for the body to make new **white blood cells**—cells that help fight infections. Often, the main source of an infection in a child with a lower-than-normal level of white blood cells is from bacteria in his or her own body.

Your child's nurse will check your child's blood cell counts regularly and tell you if the counts are low. Low blood cell counts or other signs of serious infection may delay treatment or mean that your child needs to stay in the hospital. In some cases, medicine may be given to increase the number of white blood cells after chemotherapy.

### Tips to protect your child from germs

Although it's hard to completely eliminate the risk of infection, talk with your child's nurse to learn more about these and other steps you and your child can take:

- **Wash hands well.** Always have your child and those around him (especially your family and the people on your child's health care team) wash their hands well with soap and warm water. This is especially important before eating, after using the bathroom, after being in a public place, and around pets – if allowed.
- **Stay extra clean.** If your child has a catheter, it's important to keep the area around it clean and dry. It's also important that your child's teeth are clean after meals and before going to bed. Check your child's mouth for sores or other signs of an infection each day. If your child gets a scrape or cut, make sure to clean it well, right away.
- **Stay away from germs.** Your child needs to stay away from crowds and people who are sick. You may also need to take special precautions when preparing food. For example, fruits and vegetables may need to be cooked or peeled, and meats may need to be cooked thoroughly. Help your child to eat hot foods when they are hot and cold foods when they are cold. Don't let food sit out.

## Signs of infection

Infections during cancer treatment are medical emergencies. Discuss the signs of infection with your child's doctor and know what steps to take if your child has:

- chills
- sores or white coating in the mouth or on the tongue
- cough or sore throat
- swelling or redness, especially around a catheter
- ear pain
- headache or sinus pain
- neck that is stiff or sore
- urine that is bloody or cloudy
- rash
- pain or burning when urinating
- other signs to call about: \_\_\_\_\_

\* Ask if you should take your child's temperature orally or rectally—and check with your child's nurse to make sure you are taking the temperature correctly.

## Stress

Lowering stress can improve your child's mood and help reduce pain and discomfort.

### Tips to calm your child

- **Prepare your child.** Work with your child's nurse and child life specialist to prepare your child for new treatments or tests. For example, children may visit the room where they will get treatment, touch the equipment, meet the doctors, and take part in medical play, with a **child life specialist** or nurse, before a new test or treatment.
- **Help your child to relax.** Look for ways to help your child let go of stress and frustration. Ask about activities that can entertain and relax your child. Having things to look forward to, such as calls to friends, can also help.
- **Be there for your child.** Let children know you are there for them, and that they can come to you for a hug, laugh, an honest answer, or a shoulder to cry on.
- **Get counseling support.** A social worker, child life specialist, and/or nurse can help improve your child's ability to handle stress and difficult situations. For emotional problems that last or get more serious over time, your child's health care team can give you the names of psychologists or other mental health experts who can help.

Visit the Practices That Help Children: Integrative Medicine Approaches section on page 76 to learn about more practices that may help to lower stress.



*"When our son was stressed, sometimes a scooter ride down the hall helped. Other times we played cards or wrote together."*

## Tips to help your child eat well

- **Talk with a registered dietitian.** Meet regularly with a dietitian to get practical advice and strategies to help your child.
- **Learn what types of foods and drinks are best for your child.** Most children need to eat a variety of foods, while focusing on nutrient-dense foods (such as lean meats and poultry, whole-grain breads, cereals and pasta, beans, rice, fruits, vegetables, and dairy products). Ask your child's dietitian for recipes and easy snacks that are recommended for your child.
- **Some children may be advised to get extra protein and calories.** Foods high in protein help to build and repair muscles. Foods high in calories can prevent weight loss. These include food such as eggs, cheese, whole milk, ice cream, nuts, peanut butter, meat, and fish.
- **Encourage small, frequent meals.** Smaller meals throughout the day may be easier for your child to eat than big meals.
- **Check before giving vitamins or other supplements.** Vitamin and herbal supplements may be discouraged because they can change how some cancer treatments work. For example, some vitamins interfere with absorption of certain chemotherapy drugs. However others may be safe so it is important to talk with your child's doctor.
- **Take special care with food to lower the risk of infection.** You may need to take special care as you handle and prepare food. For example, fruits and vegetables may need to be cooked or peeled, and meats may need to be well cooked.
- **Reduce side effects.** Some side effects can make eating difficult. Here are [tips to help manage side effects](#) such as appetite loss, constipation, diarrhea, mouth sores, nausea, and vomiting.
- **Call about changes.** If your child is not eating or drinking well don't wait for your child to lose weight before taking action.

## Nutrition

Good nutrition can help your child to feel better and stay stronger. Most often, good nutrition means eating a variety of foods. However, it's often difficult for children to eat well during treatment. Being upset or afraid can also make eating more difficult. At times, it may be hard to get your child to eat much at all. Some children need support such as medicines to increase appetite, dietary supplements, and IV fluids. Your child will have her weight, height, and blood checked, to assure proper growth and good nutrition.

Keep in mind these suggestions:

Be patient and praise your child when he eats well. It may take a lot of patience, creativity, and some trial and error to help your child to eat well. Don't argue with, nag, or punish your child or make her eat. Keep mealtimes calm.

Sometimes watching television or a movie can distract your child and make it easier for him to eat. Physical activities, such as walking or playing, may increase your child's appetite. Ask about activities that may be recommended to increase your child's appetite.



"In addition to drinking water, my child would drink a homemade smoothie made with fruit, milk, and peanut butter in the blender. On days when he didn't feel like eating too much, we focused on offering him healthy fluids."

## Tips to help your child drink liquids

Drinking enough liquid is extremely important. It's especially important if your child has less of an appetite, is vomiting, or has diarrhea. Losing fluid can lead to **dehydration**, a dangerous condition. If your child becomes weak, dizzy, and has dark yellow urine, he is likely dehydrated.

Take these steps to help your child drink enough liquids:

- **Learn how much liquid your child needs each day.** Talk with your child's dietitian or nurse to learn how much liquid your child should drink each day to prevent dehydration. This will depend on your child's age and other health conditions, such as if she is also losing fluids through vomiting or diarrhea.
- **Give your child choices.** In addition to drinking fluids, you can serve other liquids such as popsicles, Jell-O®, pudding, ice cream, and soup to help your child.
- **Slow may be best.** If your child has an upset stomach, try liquids first. Start with small amounts of clear liquids (water, Pedialyte®, broth, or Jell-O®). If your child can keep these down, you may want to try adding denser liquids, such as strained cereal, pudding, yogurt, or milkshakes, before slowly transitioning back to solid food.
- **Try making shakes or smoothies.** Some children find shakes or smoothies made from nutritious high-calorie, high-protein foods are easier to get down than solid foods. It may also be more fun to drink through a straw. Talk with your child's dietitian about whether to add nutrition supplements.

## Pain

Seeing your child in pain is extremely difficult. This section can help you learn how to work with your child's health care team to prevent or reduce pain that your child may have.

Controlling pain is an important part of treating children with cancer. Pain is not something that your child has to "put up with." Your child will feel stronger and better during treatment if he doesn't have pain. Pain can suppress the immune system, increase the time it takes the body to heal, interfere with sleep, and increase the chances of **depression**.

## What causes pain?

These things may cause your child pain during treatment for cancer:

- treatments, such as surgery
- procedures, such as a bone marrow aspiration or a spinal tap
- needle sticks for blood draws or injections
- side effects, such as mouth sores, constipation, or diarrhea
- cancer, such as when the tumor presses against nerves or other parts of the body

## How can I tell if my child is in pain?

Trust your judgment and observations as a parent. If you think something isn't right and your child may be in pain, talk with your child's doctor. Signs of pain vary by age.

**Very young children:** Babies and young children show discomfort by crying when touched. Or they may cry more often or have a different-sounding cry. Other signs of pain include not being able to be comforted or being withdrawn or tense. A change in sleeping or eating patterns, or tugging at a part of the body, may also be signs of pain in young children.

**Older children:** Older children will usually tell you when something hurts. Still, some children do not want to let on that they are in pain because they do not want to upset you. Older children who have pain may wince, moan, or grimace. Their eyes may be red or puffy from crying. Encourage your child to tell you or the doctor about pain.

## Who treats pain?

Pain experts may be **oncologists, anesthesiologists, neurologists, surgeons**, or other doctors, such as **psychiatrists, psychologists**, nurses, or **pharmacists**. Specialists in music or art therapy or those who practice **acupuncture, biofeedback, massage therapy, or hypnosis** may also help to reduce pain. These specialists often work together as part of a pain or **palliative care** team to assess your child's pain and develop a pain control plan.

## How is pain controlled?

Each child needs a personalized plan to control pain—based on their age, treatment, and side effects. You and your child's health care team will work together to manage your child's pain.

Over-the-counter pain medicines, such as **ibuprofen** (also known as Advil®) or **acetaminophen** (also known as Tylenol®), may reduce pain and are a good first approach. **Opioids** may be prescribed if over-the-counter medicines do not work. Talk with your child's doctor or nurse if you have concerns about the possibility of addiction to pain medicine. Not giving your child enough pain medicine can lead to pain that could have been prevented.

In addition to medicines, certain practices can be used to lower pain:

- **Distraction and relaxation.** Playing games, listening to or reading books, or watching movies may distract or take your child's focus away from the pain. Activities such as music, breathing exercises, or blowing bubbles may help to relax your child, which can lower pain, stress, and muscle tension.

- **Complementary practices such as massage or acupuncture.** These practices may be effective in lowering pain.
- **Heat and cold therapy.** A heating pad may relax muscles to help reduce pain. Cold packs may help reduce swelling and pain.
- **Exercise.** Walking and other gentle exercises increase blood flow and raise **endorphins** (substances the body makes naturally to reduce pain and give a feeling of well-being).
- **Sleep.** Being well rested may reduce children's level of pain and improve their overall sense of well-being.

Learn about more ways to reduce pain in the [Practices That Help Children: Integrative Medicine Approaches](#) section on page 76.

## What steps can I take at home to help reduce pain?

Here are some ways you can help reduce pain levels when your child is at home:

- **Follow all instructions from your child's doctor.** You may be asked to take your child's temperature and check with the doctor before giving some pain medicines. This is because some pain medicines can reduce fevers, which may mask, or hide, this sign of infection.
- **Give the pain medicine as prescribed.** Make sure your child takes the correct amount of pain medicine at the right time. Don't try to hold off, or wait until your child's pain gets too bad, before giving pain medicine. Waiting too long between doses could make the pain take longer to go away or increase the amount of pain medicine needed to lower pain.
- **Learn what side effects to expect from pain medicine.** Pain medicine may cause sleepiness, stomach upset, constipation, or gas. These side effects may lessen over time, but your child's health care team should always be told about them.
- **Use a pain scale.** Ask for a pain scale from your child's hospital that is age-appropriate. Ask your child questions such as: Where does it hurt? What does the pain feel like? How bad is the pain? When did the pain start?
- **Track your child's level of pain.** Keeping a written record of pain can help your child's health care team to develop a pain control plan for your child. Take it with you to appointments. Keep a chart, or take notes, and write down information such as:
  - the date and time your child had pain
  - your child's pain level when medicine was given
  - the type and amount of pain medicine given
  - what time it was when the pain went away or when the pain medicine was given again
  - side effects or other problems from the pain medicine



*"We use a chart at home to record Jessie's pain level and then share it with his doctors. We found that the pain medicine worked well to keep his pain under control. Acupuncture also helped. Sometimes we watched movies, which helped to distract him from the discomfort."*

## What should I call my child's doctor about?

Contact your child's doctor right away if the pain is severe and you are not able to reduce it. Uncontrolled pain is a medical emergency.

Call your child's doctor if:

- the pain isn't getting better or going away with the pain medicine
- the pain makes it hard for your child to eat, sleep, or play
- your child has new pain



*"Our child's doctor helped us control our son's pain. She was so kind. She also explained that my child wouldn't get addicted to pain medicine that was taken as prescribed. This helped me to understand that I should not try to hold off or limit his pain medicine."*

## Immunizations



*"We talked with Jasmine's nurse to learn what vaccines she and her sisters could get when she was going through treatment and which ones we needed to delay."*

**During treatment**, always check with your child's doctor before getting or refusing a vaccine.

- Your child should *not* get a live virus vaccine or have close contact with someone who has recently had such a vaccine. Measles, mumps, or chickenpox, as well as FluMist®, are all examples of live virus vaccines.
- Your child *may* be able to receive a flu shot (which is an inactive virus vaccine), as well vaccines that do not contain live viruses or bacteria such as those against diphtheria, whooping cough (pertussis), and tetanus.

**After treatment**, your child's doctor will advise you when it is safe to receive a live vaccine, based on your child's situation.

## Related resources

- [Side Effects](#)
- [Eating Hints](#)
- [Pain Control: Support for People with Cancer](#)

# Finding Ways to Cope and Stay Strong

“Being strong meant learning to rely on others. I found that friends wanted to be there for our family. All I needed to do was ask. I also met with a counselor who gave me insights and listened in ways that friends could not.”



Asking for support from others may not be easy. This section has practical advice to guide you to the help you may need during this difficult time. Staying emotionally and physically healthy can enable you to tackle the many tasks surrounding your child’s treatment.

## Getting help and support from others

Research shows what you most likely already know—help from others strengthens and encourages your child and family. Let others help during this difficult time. Family and friends may want to assist, but might not know what you need. You may want to:

- **Take the first step.** Let family, friends, and coworkers know about your child’s cancer and treatment. Share only what you feel comfortable sharing.
- **Tell people how they can help.** Keep a list of things that others can do for your family. For example, people can cook, clean, shop, or drive siblings to their activities.
- **Find an easy way to update family and friends.** You may want to use a social media site or a site such as [CarePages](#), [Caring Bridge](#), [My Cancer Circle](#), or [MyLifeLine.org](#) to update people and ask for practical help. Other sites, such as [Lotsa Helping Hands](#), make it easier to organize help from people in your community.



“My neighbor Liz is a gem. She posted updates for our friends about Calvin’s progress. She also helped friends make posters to decorate our son’s room.”

## Getting professional help

If you are not sleeping well, are often in a depressed mood, or feel irritable or anxious, talk with your primary care doctor. Your doctor can give you the names of health care professionals who can help you, such as a **psychiatrist**, **psychologist**, **family therapist**, or **social worker**. Some parents find that it helps to talk with a leader in their spiritual community.



*"I'm not the kind of person who seeks outside help. But, I was feeling so overwhelmed that I knew it was time to see a counselor to get my stress under control. Getting advice from a trained specialist really helped me get through this difficult time."*

## Joining a support group

Some support groups meet in person, whereas others meet online. Many parents benefit from the experiences and information shared in these groups. Some parents find online message boards helpful.



*"My wife and I knew we couldn't tackle this alone. We met with a support group for parents of children with cancer. Our group brings in experts, and we learn what has helped others. We're also able to post messages to an online support community that's been helpful."*

## Working to keep relationships strong

Relationships are often strained and under pressure when a child has cancer. It may help to:

- **Keep lines of communication open.** Parents often have different coping strategies. Talk about how you each deal best with stress. Make time to connect, even when time is limited.
- **Remember that no two people cope the same way.** So, if your spouse or partner does not seem as distraught as you, it does not mean he or she is suffering any less than you are.
- **Make time for loved ones.** Even a quick call, text message, or handwritten note can go a long way in making a loved one's day a good one.



*"I knew we were in trouble even before the social worker told us how many marriages fail when a child is very sick. My husband and I deal with stress in very different ways. It helped to try and understand where the other person was coming from."*

# Making time to renew your mind and body



*"I knew that in order to be there for my child and my family, I needed to reach a calm place within myself."*

It can be tempting to put your own needs on hold and to focus solely on your child. But it is important to take time for yourself so you have the energy to care for your child.

Here are some tips to get you started:

- **Find ways to relax and lower stress.** Some parents try something new, such as a yoga or deep-breathing class at the hospital. Others are refreshed by being outdoors, even for short periods. Whatever the method or place, find one that feels peaceful to you.
- **Eat well.** Good nutrition will help you keep up your energy and stay healthy. Pack a healthy snack with some fresh fruit. Avoid eating fast food whenever possible.
- **Get plenty of sleep.** See a doctor if you have trouble sleeping or feel exhausted during the day.
- **Stay active to sleep better and stay calm.** Try to walk, jog, go to the gym, or follow an exercise DVD. If it's hard to stay physically active at the hospital, try walking up and down the stairs or around the hospital or unit.
- **Fill waiting time.** Pick a few activities that you enjoy and can do in your child's room, such as playing a game, reading a book or magazine, writing, or listening to music.
- **Get feelings out.** Write or draw, or choose another way to express your thoughts and feelings.
- **Rely on your faith or belief system.** Some people find that cancer brings a new or deeper meaning to their faith. Others feel that their faith has let them down. Some parents pray, read religious books, meditate, or talk with spiritual leaders. Sometimes writing in a journal, reading, or simply being still can help.

## Related resources

- [Coping with Cancer](#)
- [When Someone You Love Is Being Treated for Cancer: Support for Caregivers](#)

# Helping Your Child to Cope



*“Our child met other cancer survivors who are leading amazing lives despite, or perhaps because of, all they have been through. It helps to see yourself in a hero.”*

Treatment brings many changes to a child's life and outlook. Changes to your child's daily routine, appearance, and friendships may be especially challenging to deal with. Not being able to go to school or do other normal activities can make your child feel alone. Long hospital stays and time away from friends and family can also take their toll.

You can help your child by letting her live as normal a life as possible. Although many activities may need to be changed, new activities and people can be added in their place. Talking with other families who are going through similar events may also be beneficial.

Here are some ways to help your child:

- **Learn what to expect.** Ask how the type of treatment your child is receiving has affected other children, so you can prepare your child.
- **Be open and ready.** Encourage, but don't push, your child to share his feelings. Be there when your child comes to you.
- **Check out activities at the hospital.** Learn about events and programs at your child's hospital.
- **Take care of yourself.** Children sense when their parents are stressed. It helps them cope knowing that their parents and siblings are getting support.

## Changes in appearance



*“Often a fun cap, a new outfit, or make-up can lift your child's spirits.”*

It helps to feel good on the outside, even—or perhaps especially—when your child feels down and tired on the inside. Children can be sensitive about how they look and how others respond to them.

Here are some ways to help your child:

- **Prepare for hair loss.** If treatment will cause your child's hair to fall out, let your child pick out a fun cap, scarf, and/or wig ahead of time. Try to pick out a wig before the hair falls out, so you can match it to their hair color. Sometimes cutting your child's hair short before treatment helps make hair loss a bit less upsetting.

- **Be aware of weight changes.** Some treatments may cause weight loss and others may cause weight gain. Get advice from a dietitian so you know what to expect and how you can help your child prepare for and cope with physical changes.
- **Be creative.** You and your child may shop for outfits that your child likes. Sometimes a cool t-shirt or fun hat helps to build self-esteem.

## Changes in friendships



*“Sometimes your child will make a new best friend. Sometimes friends your child thought would be there for them are not. Other times you may experience the kindness of strangers.”*

Your child's friendships are tested and may change during a long and serious illness. Sometimes, it may seem as though your child's old friends are no longer "there for them" or that they don't care anymore. Your child's friends might not know what to say. Or they might be afraid of saying the wrong thing, so they say nothing at all. Unfortunately, some children speak before they think or before they have the facts. No matter the reason, it can hurt when classmates and friends seem uncaring. Sometimes, it may seem as though your child's friends are moving on with their lives, and your child is left out. It may help if your child takes the first step and reaches out to friends.

The good news is that your child may make new friends through this experience. Going to support groups is one way to connect with others. Some groups meet in person and others meet online. Your child's social worker and child life specialist are also sources of support and guidance. For example, they can role-play conversations with your child that may be helpful.

Here are some steps you can take with your child:

- **Help your child stay in touch with friends.** You can encourage and help your child to connect with friends through texts, e-mails, online video chats, phone calls, and/or social media sites. Sometimes a social worker or child life specialist can help your child think through what they would like to share with friends. If possible and when your child is up to it, friends may be able to visit.
- **Help your child know how to respond.** Sometimes people will stare, mistake your child's gender, or ask personal questions. Talk with your child and come up with an approach that works. Your child may choose to respond or to ignore comments.



*“At first Meg’s friends came around often. But as the school year went on, her friends got involved in their own activities and visited less. The girls were nice kids. They continued to call, but it got harder to have things in common the longer Meg was out of school. Meg found she had more in common with new friends she made at the hospital.”*

## Changes in feelings



*“Try to stay upbeat, yet keep it real. Don’t put on a mask, or your child will put one on too. And, by the way, it’s okay to be silly too!”*

Although over time many children cope well, it's common for your child to feel anxious, sad, stressed, scared, or become withdrawn, from time to time. Talk with your child about what they are feeling and help them find ways to cope. You and your child can also meet with a social worker, child life specialist, or psychologist about feelings that don't have easy solutions or seem to be getting worse over time. These specialists can help your child manage difficult feelings before they cause physical problems, such as changes to sleeping or eating habits, anxiety, or depression.

Reassure children that they can always come to you. Listen and be open to what your child has to say. Some children prefer to express their feelings through drawing, painting, writing, or playing music.

Try these tips to help your child cope with difficult emotions:

- **Find ways to distract or entertain your child.** Playing video games or watching movies can help your child to relax. Practices such as muscle relaxation, guided imagery, and biofeedback may also help. See the [Practices That Help Children: Integrative Medicine Approaches](#) section on page 76 to learn more.
- **Stay calm.** Your child can feel your emotions. If you often feel sad or anxious, talk with your child's health care team and your doctor about the best way to manage these emotions. However, if you often hide your feelings, your child may also hide their feelings from you.
- **Get help if you see signs of depression in your child.** It is normal for your child to feel down or sad sometimes, but if these feelings last for too long and happen on most days, they may be a sign of **depression**. Depression is a medical illness that can be treated. Child life specialists, social workers, counselors, psychologists, psychiatrists and other specialists are all people who can give your child extra support during this difficult time.

### Signs of clinical depression include

If your child has any of these signs, talk with the doctor.

- no longer enjoying activities that your child used to enjoy
- changes in eating or sleeping habits (e.g., not sleeping well)
- feeling or acting sad, nervous, sluggish, or tired
- feeling worthless or guilty, even for things that are no one's fault
- having trouble paying attention
- talking about death or suicide

# Changes in schedule (hospital and school)

Your child may spend more time at the hospital and less time at school during treatment. Here are some ways to help your child cope with long stays at the hospital and time away from school.

## Hospital stays

Being in the hospital can be difficult for anyone, especially children. It is a different setting, with new people and routines, strange machines, and sometimes painful procedures.

Try these tips to make your child's time away from home a bit easier:

- **Bring in comfort items.** Let your child choose favorite things from home, such as photos, games, and music. These items can comfort children and help them to relax.
- **Visit game rooms or play rooms.** Many hospitals have places where children can play, relax, and spend time with other children at the hospital. These rooms often have toys, games, crafts, music, and computers. Encourage your child to take part in social events and other activities that are offered at the hospital.
- **Decorate your child's room.** Ask if you can decorate your child's hospital room. Posters, pictures, and other decorations may brighten the room and help cheer up your child. Window markers are a fun way to decorate windows. Check to see what items can be brought into your child's room, since there are sometimes medical restrictions.
- **Explore new activities.** If sports are off-limits, learn about other activities that can help your child stay active and have fun. Your child may also enjoy listening to music, reading, playing games, or writing. Some children with cancer find new skills and interests they never knew they had.

## Missing school

Most children with cancer miss school during treatment. Some children are able to attend from time to time, whereas others need to take a leave of absence.

Here are some ways to get the academic support your child needs during treatment:

- **Meet with your child's doctor.** Find out from the doctor how treatment may affect your child's energy level and ability to do schoolwork. Get a letter from the doctor that describes your child's medical situation, limitations, and how much school your child is likely to miss.
- **Learn about assistance from the hospital and your child's school.** Some hospitals have education coordinators and others have nurses who will tell you about education-related resources and assistance. Ask about an **individualized education plan (IEP)** for your child. This is an education plan for children with certain health conditions or disabilities. It describes what special services are needed (such as special class placement, extra help with class assignments and tests, tutoring, and other services such as counseling, speech therapy, and physical therapy) and how these services will be provided to your child.

- **Keep your child's teachers updated.** Tell your child's teachers and principal about your child's medical situation. Share the letter from your child's doctor. Learn what schoolwork your child will miss and ways for your child to keep up, as they are able. Talk with people at the school and hospital to make a plan that meets your child's educational needs both during and after treatment.

## Going back to school

It's best for most children with cancer to return to school as soon as they are able. It helps to have a routine and to be with other children. Still, the adjustment may be challenging. Your child may have fallen behind and have low energy. Friendships may have changed. Children often feel self-conscious about changes in appearance and weight.

Ways to help your child get back into the swing of things at school:

- **Learn about back-to-school programs** offered by many hospitals. These programs help classmates and teachers learn about cancer and make your child's return to school easier.
- **Talk with your child's school** so they can give your child any needed support. The teachers can also talk with your child's classmates and help them welcome your child back. School counselors and school nurses may also be a big help.
- **Talk with parents of classmates** to let them know your child is coming back to school. Plan times for your child to get together with classmates, to catch up and play.
- **Check out the in-depth information links** on educational issues and school for children with cancer listed below.



*"Hong was eager to go back to school, even during treatment, so we wrote up an emergency action plan and gave copies to his teachers and the school nurse."*

## Related resources

- [School Support \(COG\)](#)
- [Educating the Child with Cancer \(ACCO\)](#)

# Helping Brothers and Sisters



*“When a child is diagnosed with cancer, everyone in the family needs healing, including the siblings.” ([SuperSibs!](#))*

As a parent, you want to be there for all of your children, but this can be difficult when one of your children is being treated for cancer. You may notice that your other children are having a difficult time—but not know what to do. Simply telling your other children that you know how difficult it is for them, and that you love them, can be comforting.

Even small amounts of time and attention can make a big difference in helping your other children. This section addresses the needs and feelings of siblings—and suggests ways to help them.

Although many, probably most, siblings cope well—some do not. Be proactive and talk with a counselor at your child’s school, your child’s pediatrician, or a social worker at the hospital. They can give you advice and help you find local programs, support systems, counseling, and other services that may help.



*“At times I felt like this situation was harder on our daughter, Aaron’s sibling, than it was on us. We struggled to have the energy and time for her. I felt guilty. I realize now that there were conversations we could have had, and things we could have done, that would have made a big difference in her life.”*

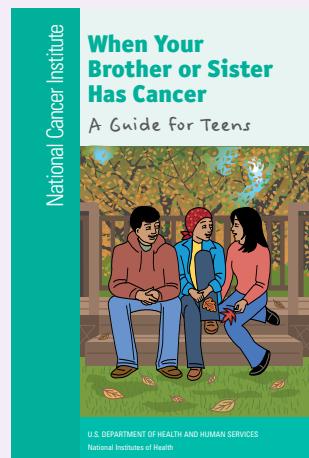
## A booklet made for siblings

This booklet can help siblings when their brother or sister has cancer. Although designed for teens, it can also be used with younger children.

In this guide, siblings can:

- learn what has helped other siblings
- get ideas about how to deal with changes in the family
- read tips about what to say when friends ask tough questions
- learn about cancer and how it's treated

You can view parts of this guide [online](#). You can also [download](#) or [order free copies of this booklet](#).



## How your well children may feel

We know that siblings of a child with cancer face many difficulties. Many are sad, scared, and confused. Although many try to be brave and helpful, they may feel left out and alone.

Your child's siblings may feel:

**Scared** about what might happen to their brother or sister

**Guilty** about being healthy and having fun

**Mad** that this is happening to their family

**Sad** for their brother or sister

**Worried** that they will get cancer too

**Alone**, neglected, ignored, and left out

**Lonely** because they are seeing less of their parents and friends

**Embarrassed** about the way people stare at or talk about their sibling

**Jealous** about the attention and gifts their brother or sister receives

**Concerned** about what is happening to their family

**Overwhelmed** with all of the changes

In addition to these feelings, you may also notice changes in a sibling's behavior. Are your well children having trouble sleeping? Does your previously outgoing child now seem quiet and withdrawn? Have you noticed any changes in your child's grades at school? Does a formerly good student suddenly stop doing her homework, either to get your attention or because she is having trouble concentrating?

Check in regularly with your children to see how they are coping, and talk about any changes you notice. Ask them what is most difficult about what is happening. Talk about ways you can work together to help each other. Seek help from your child's **pediatrician** for problems that last or get worse over time.

## Ways to help siblings



*"Talk with your child's teachers. Get help from other adults you trust and respect. My neighbors pitched in and made sure homework got done and kids got to their activities."*

These suggestions have helped other families:

- **Listen to and talk with your other children.** Set aside some time every day, even if it's just a few minutes, to spend with your other children. Tell and show them that they are loved. Ask how they are feeling, even if you do not have an easy solution. Sometimes, just listening is very important.

- **Keep them informed and involved.** Talk with your other children about their sibling's cancer and tell them, as best you can, what to expect during treatment. If possible, find ways to include them in visits to the hospital. If you are far from home, stay connected through e-mails, texts, and phone calls.
- **Keep things as normal as you can.** Arrange to keep your other children involved in school-related events and other activities that are important to them.
- **Seek out support from health care professionals.** Be proactive and talk with your children's pediatrician as well as a social worker at the hospital where your child is receiving cancer treatment. Get suggestions for local programs, activities, and counseling services.
- **Talk with friends, family, teachers, coaches, clergy, and others.** Ask key people in your family's life to give siblings extra support. Most people want to help and will appreciate being asked. Keep in mind that some teens may not want people outside the family to know what is going on at home. Talk with your children if you plan to reach out to others, such as teachers or coaches, on their behalf.

Some people who can help siblings of a child with cancer may include:

- grandparents, aunts, uncles, cousins
- friends and neighbors
- parents of your children's friends
- teachers and coaches
- people from your religious community
- school nurses
- guidance counselors at school



*"Gail and Matt were able to relax and have a good time when they went camping with our neighbors. I think being out in nature, hiking, and relaxing for a weekend was just what they needed."*

## Related resources

- [When Your Brother or Sister Has Cancer: A Guide for Teens](#)
- [Depression \(PDQ®\)](#)

# Getting Organized



*“The hospital kept records, and so did we. I used my phone and computer to keep track of medical tests and treatment details. I also kept a file on my computer where I entered key medical information. It came in handy with all the different doctors my child saw.”*

As challenging as it may be, keeping a record of the medicines, tests, and treatments your child receives is extremely important. So too is organizing medical bills and insurance information. This section has tips to help you keep track of both medical and financial-related information.

## Tracking key medical information

Keep track of the medical care your child receives. Some parents write important information in a notebook. Others prefer to organize this information on their computer or phone. You can also set up a **personal health record (PHR)** that allows you to enter, manage, and track your child’s important medical information. A PHR is similar to an **electronic medical record** that your child’s doctor or insurance company may keep, except that with a PHR, you are the one who keeps it and controls access to it.

Increasingly, health care providers, insurance companies, and employers are providing parents with access to electronic tools. Talk with your child’s social worker or a financial officer at the hospital to learn more about ways to track key medical information. What is important is not the exact tool you use but that you keep key medical information organized and accessible.

Many parents also keep a journal and calendar. For example, you may keep a journal where you write down details about side effects your child is having or questions to ask the doctor. Calendars can be used to track daily events and/or important dates to remember. You can learn more about these and other eHealth tools in the [Related resources](#) section on page 65.

## Track medical care

On the next page is a chart of the type of information that is helpful to keep handy and up-to-date. For example, you should ask for and keep copies of scans, pathology reports, and treatment plans. Keep these in a file folder, or scan them into images that you save on your computer.



*“I was overwhelmed with bills and paperwork, so I asked my brother for help. He was great at comparing itemized bills from the hospital with statements from the insurance company. He organized all the information, and called the hospital and insurance company when things did not match up. This was one less thing I had to worry about.”*

## Medical visits

| Type of visit/date | Provider's name | Reason for visit |
|--------------------|-----------------|------------------|
|                    |                 |                  |
|                    |                 |                  |

## Tests, procedures, and related lab reports (such as CT scans, MRIs, blood counts)

| Test or procedure | Date/time | Results | Notes |
|-------------------|-----------|---------|-------|
|                   |           |         |       |
|                   |           |         |       |

## Treatments (include names and amounts of chemotherapy given, as well as doses and area(s) treated with radiation therapy, for example)

| Treatment(s) | Date/time | Side effects | Notes |
|--------------|-----------|--------------|-------|
|              |           |              |       |
|              |           |              |       |

## Medicine

| Medicine(s) and dose | Date/time | Side effects | Notes |
|----------------------|-----------|--------------|-------|
|                      |           |              |       |
|                      |           |              |       |

## Other supportive or complementary care received

| Type of care received | Date/time | Notes about the care |
|-----------------------|-----------|----------------------|
|                       |           |                      |
|                       |           |                      |

In addition to tracking ongoing medical care, it's helpful to keep a sheet with this key information handy for yourself and others:

- names and contact information for the people on your child's health care team
- diagnosis information
- treatment plan
- life-threatening health issues for which urgent medical care should be sought

## Track medical bills

It is important to understand your health insurance policy and to develop an organized way to pay and/or follow-up on bills. This means first reading and understanding what is in your health insurance policy. Call your insurance company and ask about anything you are unsure about. It may also help to:

- Talk with a benefits coordinator at your workplace or insurance company. Learn which tests and treatments are covered by your policy and which, if any, are not covered.

- If the doctor requests a test or procedure that is not covered by your insurance policy, ask the doctor to write a letter stating why it is needed, and submit this to the insurance company. If the insurance company does not agree to cover the treatment or procedure, you can go through the insurance company's appeals process.
- Ask to have one case manager at the insurance company assigned to you so you can talk with the same person each time you have a question or concern.
- Develop a system to track medical bills. Doing so may prevent billing problems. Most parents find it helpful to keep paperwork in one place. If you get your medical bills in the mail, put them in a single folder or binder. If you get your bills online, store them in a file folder on your computer. Some parents find it helpful to create a separate e-mail account to communicate with their child's hospital and the insurance company.
- Organize these items by date:
  - bills from the hospital
  - explanation of benefits (EOB) statements from your insurance company
  - receipts for payments that may be tax-deductible

Match each bill to an explanation of benefits statement from your insurance company. Ask about any differences between these two documents. You may find it helpful to keep a chart such as the one below.

| Name and phone number of person called (at hospital or insurance company) | Date & time | Issue discussed | Next steps |
|---|-------------|-----------------|------------|
|   |             |                 |            |
|   |             |                 |            |
|   |             |                 |            |

Cancer treatment can be very expensive, even if you have insurance. Talk with the business office at the hospital to learn about different payment options. Find out what arrangements can be made to pay medical bills. Ask a social worker at the hospital for help with financial or insurance issues, and to find outside organizations and resources that can help. You can also learn about organizations that offer financial assistance on our list of [Organizations That Offer Support Services](#).

## Related resources

- [Organizations That Offer Support Services](#)  
(Choose from a list of services.)
- [What Is an Electronic Medical Record \(EMR\)?](#)

# Survivorship and Follow-up Care

*"I think that life will always have a little part of the cancer experience in it. At first that seemed like a bad thing, but now I realize it's taught me a lot. Every day, I see Jack having fun as a kid again, makes me happy."*



The completion of your child's cancer treatment is something to celebrate! However, it may also be a time that brings new challenges. You may worry that the cancer will return. Your child may struggle to get used to new routines. Some families enter this new phase feeling stronger, whereas others are more fragile.

Many families are surprised by anxious feelings that arise during this long-awaited time, when they expected to feel only relief. Instead of this being a time to go back to life as it used to be, it may be a time of continued adjustment, as you leave the security of the people on your child's health care team. Some said the transition to life after treatment took longer and was more challenging than they thought it would be.

This section has tips and information about follow-up care and survivorship care programs for children who have been treated for cancer.

## Adjusting to a new normal



*"I stopped worrying and helped my child get on with life. I learned to focus on each day and to be grateful for my son's healing."*

Treatment has been successful and your child and family enter a new phase of life. You may feel both joyful and anxious. Your child may still be healing, both physically and emotionally. Your family may be facing new challenges.

Some children get back into school and home routines easily and quickly. For others, the transition is more difficult and takes longer. Parents and siblings also go through a period of adjustment. For example, siblings may have become more independent while you were away at the hospital. Take time to talk about special things that each person in your family has done during treatment. This can help to set in motion a positive tone of resiliency for the future.

## Tips that help families adjust after treatment

- **Celebrate.** Find special ways to mark the end of treatment. Recognize each person in your family. Celebrate their accomplishments at the hospital or at home with family and friends. Find a way to thank the people on your child's health care team.
- **Get informed.** Learn about organizations that support survivors and their families in the [Related resources](#) section on page 71.
- **Get emotional support.** Talk with a professional counselor or join a support group.
- **Live in the present.** Take things one day at a time. Try to focus on today.
- **Help others.** Some parents find ways to give back and help others. Parents often say that giving back is what helped them the most.

## Follow-up care after cancer treatment



*"It was not only reassuring, it was essential for our daughter to receive follow-up care from specialists who see children after treatment for cancer. Each time she goes back for check-ups and the tests come back normal, we breathe a sigh of relief."*

Get a written copy of your child's treatment summary and survivorship care plan. Ask for recommendations to hospitals that offer the type of follow-up or survivorship care that your child needs to receive.

### Treatment summary

The treatment summary includes both diagnostic and treatment information such as:

- type of cancer, severity (stage, grade, or risk group), date of diagnosis, and pathology report
- type(s) of treatment received, including the names and doses of all medications, as well as the total amounts and sites of any radiation therapy received
- treatment dates
- key reports and scans (such as x-ray, CT scan, and MRI)
- side effects and/or complications experienced during treatment
- supportive or palliative care—such as counseling or physical therapy, for example
- identifying number and title of the clinical trial, if your child was in a clinical trial
- names and contact information of key people on your child's health care team

## **Survivorship care plans**

A survivorship care plan (also called a follow-up care plan) is developed for each child. This plan and schedule is based on the type of cancer and treatment received. For example, some children may need to return for visits each month for the first year after they have completed treatment. Others may not need to return as often.

However, all children treated for cancer need to receive follow-up care. This care, as outlined in the Institute of Medicine's [Cancer Survivorship Care Planning](#) fact sheet, includes:

- exams and tests/procedures to check for the **recurrence** or **metastasis** of cancer, and a schedule of when they are needed
- care and support to manage any **long-term side effects** and check for **late effects**
- **psychosocial** support or counseling, and referrals as needed
- legal aid or financial support, and referrals as needed
- referrals to, and coordination with, specialists such as cardiologists, education specialists, **endocrinologists**, **physical therapists**, and **psychologists** and to appropriate treatments, clinical studies and **rehabilitation specialists**
- recommendations for healthy behaviors, such as advice regarding nutrition and physical exercise
- family-based care, education, and outreach to your child and family

## **Survivorship care programs**

Follow-up care clinics (also called long-term follow-up clinics or survivorship clinics) provide follow-up care for children who have been treated for cancer. At these clinics, your child will see specialists (in **cardiology**, **endocrinology**, **fertility**, **nutrition**, **psychology**, and/or **pulmonology**, for example) who will monitor your child's health. These clinics are usually found within hospitals. If the hospital where your child was treated does not have such a clinic, ask your child's doctor to recommend one. You can also refer to the Children's Oncology Group's [Directory of Services](#) to find a hospital that offers services [late effects of treatment](#).

## **Long-term and late effects**



*"We noticed that schoolwork was difficult for Meg. Her nurse at the survivorship clinic told us about testing and steps to get support from our child's school."*

Although many side effects go away once treatment has ended, **long-term side effects**, such as fatigue, may take some time to go away. Other side effects, called **late effects**, may not occur until months or even years after treatment.

## Factors that affect the risk of late effects

The risk of late effects depends on factors related to the type of cancer your child had, how it was treated, as well as personal factors. These include:

- **cancer-related factors** such as the type of cancer, where it was in the body, and how it affected tissues and organs
- **treatment-related factors** such as the type and dose of treatment(s), or the type of surgery
- **patient-related factors** such as your child's gender, age at diagnosis, length of time since diagnosis/treatment, personal and family health history, and health habits

## Types of late effects

Knowing what symptoms to be aware of and when they may occur can help you plan for the needs of your child. Not knowing what to expect can cause anxiety for some parents. However, for others, knowing about late effects that may or may not happen to their child in the future can be overwhelming. Many parents find it helpful to ask their child's doctor what late effects to focus on at each step of their child's recovery.

Late effects may be physical, emotional or cognitive.

- **Physical late effects** involve changes to organs, tissues, and/or body functions. They may affect your child's growth and development. Some children who have been treated for cancer have many physical late effects, whereas others have relatively few. As you talk with your child's doctor to learn what to expect, you can learn more about treatments that may increase the risk of physical late effects in [Late Effects of Treatment for Childhood Cancer](#).
- **Emotional late effects** include changes to your child's mood, feelings, and actions. Many children are very resilient after cancer treatment. Others experience social and/or emotional problems. If your child is not sleeping well and no longer enjoys activities that he once did it is important to talk with your child's doctor about having your child evaluated for **depression**. Some children develop **post-traumatic stress disorder (PTSD)**. This anxiety disorder arises in reaction to physical injury or severe mental or emotional distress. Symptoms of PTSD may include having flashbacks about diagnosis or treatment, avoiding places that are reminders of the experience, and being fearful, irritable, unable to sleep, or having difficulty concentrating. Ask your child's health care team to suggest resources for mental health support in your area.
- **Cognitive late effects** include changes in your child's ability to memorize, learn, and think. These types of late effects are more likely to occur in children who've had certain cancers such as brain and spinal cord tumors, head and neck cancers, and some types of leukemia, like **ALL**. Treatments such as radiation therapy to the head and certain types of chemotherapy also increase the risk of cognitive late effects. These late effects are also more likely in children who were very young during treatment, who received very high doses of treatment, and whose treatment lasted for a long time. Children with cognitive late effects may have a more difficult time:
  - memorizing or remembering

- learning (handwriting, spelling, reading, vocabulary, and/or math may be particularly challenging)
- thinking (including concentrating, completing work on time, doing work that involves multiple steps, problem solving, and planning)

## Questions to ask when your child has completed treatment

### About treatment

- Who should we talk with to get a comprehensive record of treatment(s) and medications that our child received during treatment? \_\_\_\_\_

### About practical steps to take at home

- What health problems in our child should we be aware of? \_\_\_\_\_
- Who should I contact if health problems occur? \_\_\_\_\_
- Does my child need to continue taking any medicine(s)? If so, for how long? \_\_\_\_\_
- What types of activities may help my child? Are any activities not recommended? \_\_\_\_\_
- What vaccines should my child receive? When should they be given? \_\_\_\_\_

### About follow-up care (plan and schedule)

- Who should I talk with to get a follow-up care plan and schedule for my child? \_\_\_\_\_
- What medical experts should my child see for follow-up care? \_\_\_\_\_
- What tests will be done during follow-up care visits? How often and for what reason? \_\_\_\_\_
- Where should my child go for follow-up care visits? \_\_\_\_\_
- What is the schedule for these visits? \_\_\_\_\_

## About possible long-term and/or late side effects

- Is my child at increased risk of having **long-term side effects**? If so, which ones and how can they be managed? \_\_\_\_\_
- Is my child at increased risk of developing **late effects** later in life? If so, which ones? How likely are these to occur? How long after treatment might they occur? \_\_\_\_\_
- What type of specialists should my child see to manage these effects? \_\_\_\_\_

## About support and coping

- What survivor support groups are available for my child? For our family? \_\_\_\_\_
- What are the benefits to my child of receiving professional counseling? Is this something you recommend for my child? Why or why not? \_\_\_\_\_

## Related resources

- [Follow-up Care After Cancer Treatment](#)
- [Late Effects of Treatment for Childhood Cancer \(PDQ®\)](#)
- [Introduction to Long-Term Follow-Up After Treatment for Childhood, Adolescent, or Young Adult Cancer \(COG\)](#)
- [Long-Term Follow-up Guidelines \(COG\)](#)
- [From Cancer Patient to Cancer Survivor: Lost in Transition \(IOM\)](#)

# If Treatments Aren't Working

*"It felt like we were giving up, but I knew we weren't. The doctors were honest with us. They told us that Devon was not going to live much longer. I'm glad we didn't put our son through treatment that would have made him feel even worse, during the precious time he still had."*



Although treatment helps many children with cancer, it may not work for all children. If the cancer your child has cannot be cured or controlled, it may be called **advanced cancer** or end-stage cancer. This section suggests ways you can help your child and make choices about end-of-life care.

## Ways to help your child

There are many things you can do to help your child. Exactly what you choose to do, and when, is a very personal choice. Here are suggestions that have helped others during this difficult time:

- **Ask for help and support.** The people on your child's health care team have helped other families facing similar situations. Talk with them to learn what can help your child and family cope with end-of-life decisions, concerns, and emotions.
- **Be honest with your child.** Because you want to protect your child, it may be hard to know how to talk with him about the fact that treatment is not working. Work with your child's health care team to get truthful information that your child can understand. Talking honestly with your child, as hard as this may seem, can actually help your child.
- **Help your child to open up.** Your child may be picking up cues from friends, family, and others that treatment is not going well. Some children choose to remain silent about what they know or suspect because they do not want to upset you or see you cry. Children may try to protect you from their own worries or fears. Letting your child know that she can share anything with you can help her feel less scared and alone.
- **Let your child have fun.** Take cues from your child. If he feels up to doing something, encourage it—and if he doesn't, let that be okay too. If there is a birthday or holiday that your child is looking forward to, feel free to celebrate that day earlier. For example, it may mean celebrating Christmas in July. Talk with your child about what would be meaningful to her. There are wish fulfillment organizations that may be able to help your child's wishes and dreams come true.
- **Share your spiritual beliefs.** Your spiritual beliefs may comfort and help your child, just as they do you and others in your family. Some parents find it helps to have a member from their religious community talk with their child and family.
- **Keep making memories.** Talk about fun times and special memories. Talk about the many people that your child means so much to. If your child feels up to it, write, draw, or make a photo book together. Talk about special things your child has done that people will always remember. Some children choose to write letters or give some of their toys to the people they love.

- **Take it one day at a time.**

As you go through this time, remember to care for yourself. You have come a long way and you are doing an amazing job. You are stronger than you think. Choose to make the most of each day, living fully in the present—and in so doing, helping your child to do the same. Sometimes simple things are the most meaningful, for both you and your child.

## Planning guide

Many teens find it hard to be open about their preferences, for medical care. Honest conversations can help teens think through and express their thoughts about what they most want. [Voicing My Choices™](#) is a planning guide that may help with difficult conversations about end-of-life issues. Topics include treatments your child may or may not want to endure, where he would want to be if the end-of-life were near, and how your child wishes to be remembered. Having a guide to help share thoughts, hopes, preferences, and wishes can help you and your child make decisions that reflect what is most important to your child.

*“Treatment wasn’t working anymore for our son. The doctor told us that he would not survive. That was the worst day of my life. Still, I knew I had to be strong. When we talked with Ryan he asked if we would keep running in a race that gives funds to his hospital. Ryan used to love running in this race, even before he had cancer. So now, each year, we continue to run.”*



## End-of-life care



*“No words really for this time. It was hard for all of us. Somehow, the doctors and nurses helped us come together so that our son knew how deeply he was, and is, loved.”*

When children have a terminal diagnosis (usually defined as having a life expectancy of 6 months or less) and are approaching the end-of-life, they may be eligible to receive **hospice** care. This type of care provides medical, emotional, and spiritual support. Hospice care helps your child to be as comfortable as possible near the end-of-life, when treatment is no longer controlling the disease. It focuses on caring, not curing. However, if your child’s health improves, hospice care is discontinued and active treatment resumes.

## Hospice care is very individualized

Hospice care may be given at your home, in the hospital, or in a hospice center. Hospice services include medical and nursing care, home health care services, medical supplies and equipment, drugs to help manage symptoms, spiritual support, counseling, social work services, and **respite care**, for example. Your family is also an important focus of hospice care. Your child’s hospice

team may include doctors, nurses, home health aides, social workers, clergy or other counselors, and trained volunteers. A hospice team member is on call 24 hours a day, 7 days a week.

More detailed information about end-of-life care is included in the [Related resources](#) section below.

## Questions to ask about end-of-life care

### About active treatment

- What is the best possible result if we continue with active treatment? What is the most likely result? \_\_\_\_\_  
\_\_\_\_\_
- Are there other active treatments you would recommend, with possibly better outcomes? \_\_\_\_\_  
\_\_\_\_\_
- How will continuing active treatment affect my child's quality of life? \_\_\_\_\_  
\_\_\_\_\_

### About end-of-life care

- What is end-of-life care? What is hospice care? \_\_\_\_\_  
\_\_\_\_\_
- What type of care would you recommend for my child? Why would you recommend it? \_\_\_\_\_  
\_\_\_\_\_
- Would you help me talk with my child about this type of care? \_\_\_\_\_  
\_\_\_\_\_
- What quality of life will my child have during end-of-life care? \_\_\_\_\_  
\_\_\_\_\_
- What care will be given to help my child be comfortable? Will my child be alert? \_\_\_\_\_  
\_\_\_\_\_
- What educational resources would you recommend to help our child and family? \_\_\_\_\_  
\_\_\_\_\_

## Related resources

- [End-of-Life Care for People Who Have Cancer](#)
- [Making Decisions about End-of-Life Care \(COG\)](#)
- [Palliative Care: Conversations Matter®](#)
- [Voicing My Choices™](#)

## Looking Forward



*“Some of the carefree innocence of childhood is gone, but in its place our daughter has gained wisdom, grace, and courage.”*

It may be hard to imagine at first, yet once your child completes treatment, you will likely find yourself thinking less and less about cancer. Over time, the current demands and joys of life will grow in importance. Some memories will fade. Others will remain. Some parents say they still worry about cancer. Others say it is a worry they choose not to nourish.

You and your family may appreciate life more deeply. You may find yourself reflecting on the kindness of family, friends, and even strangers. You may think about how brave your child was. You may remember how you relied on your faith and courage to get you through.

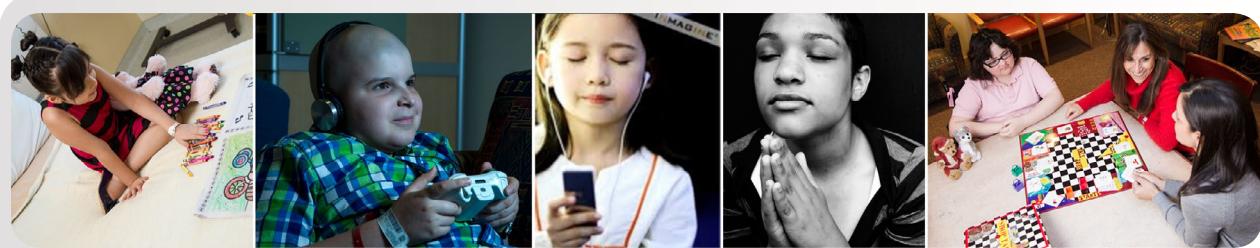
As the months and years pass, and your child stays healthy, cancer no longer takes center stage. Still, you may choose to remember certain days, such as the day of diagnosis or the last day of treatment—and do something special on those days. You can choose to remember and think back in different ways. Some families spend a day in the park. Others write, get together with friends, take a trip, or do something for others. There is no right or wrong way—there is only the way that feels and works best for your child and family.



*“While our family would never have chosen this path, once we stopped fighting it and faced it together, we somehow found our way. We came out changed. Stronger.”*

# Practices That Help Children: Integrative Medicine Approaches

Integrative medicine approaches can help your child feel better during treatment. This care is given in addition to standard medical treatment which may include chemotherapy or radiation therapy. It does not replace these treatments. For example, your child may receive acupuncture to help lower side effects caused by cancer treatment.



*“Our child’s social worker explained that complementary approaches were given in addition to, not instead of, treatment. We were glad these were used to help our child during treatment.”*

## Integrative practices that may help children during treatment

Your child’s health care team will talk with you about ways to help your child cope during treatment. Based on your child’s age, symptoms, and preferences – some practices that may be suggested include:

- **Acupuncture** is the technique of inserting very thin needles (about the thickness of a hair) through the skin at specific points on the body to control pain and other symptoms. It is based on the belief that vital energy flows along pathways in the body and that health problems occur when this energy is blocked. Acupuncture does not hurt, and even children who are afraid of needles can get acupuncture. It may help lower fatigue, pain, and nausea. Learn more about [acupuncture](#).
- **Art therapy** uses the making of art and a child’s response to art to improve her physical, mental, and emotional well-being. Art therapy is sometimes used together with **psychotherapy**. Your child can make art alone or with an art therapist. Art therapy may help lower stress, pain, and fear. It may improve communication and social interactions.
- **Biofeedback** is a method that helps children learn how to control some bodily functions, such as their heartbeat, blood pressure, muscle tension, sweating, and temperature. While learning this technique, your child will be connected to a machine that monitors these functions. Once children learn how to control their body, they may use biofeedback to lower pain and to relax. Learn more about biofeedback and other [relaxation techniques](#).

- **Cognitive behavioral therapy (CBT)** is a type of psychotherapy that helps children change the way they think and feel about certain problems and situations. It is used to treat mental, emotional, personality, and behavioral problems. Learn more about cognitive behavioral therapy and other [psychotherapies](#).
- **Deep breathing** is a relaxation technique that can help boost oxygen levels, which can help your child to relax. Your child takes deep, slow breaths in through the nose, and breathes out through the mouth. Small children can practice deep breathing by blowing bubbles. These exercises may help lower stress and increase relaxation. Learn more about [relaxation techniques](#), including deep breathing.
- **Distraction therapy** is a method that can help a child take her mind off painful or unpleasant things by providing a pleasant sensation or interesting activity to capture her attention. Babies can be touched, rocked, or rubbed. Children can play games, watch a movie, read, or do other activities that help them focus on something other than the procedure or the discomfort it may cause. Distraction therapy may help lower pain, fear, and nausea. Learn more about [distraction](#).
- **Guided imagery** (also called visualization) is a technique in which your child focuses on positive images (such as a fun place or experience) in her mind. These pleasant images can replace distressing thoughts. Guided imagery may help lower stress, pain, and nausea—and give your child a sense of well-being. Learn more about guided imagery and other [relaxation techniques](#).
- **Hypnosis** (also called therapeutic hypnosis or hypnotherapy) is a trance-like state of deep relaxation. While under hypnosis, with the assistance of a clinical hypnotherapist, your child may feel calm, relaxed, and more open to suggestion. Therapeutic hypnosis may help lower stress, anxiety, and pain. Learn more about [hypnosis](#).
- **Laughter therapy** (also called humor therapy) is actually a type of therapy that can help muscles relax and make a child feel less scared. Laughter also causes the body to release **endorphins**, which can help to lower pain. Books, songs, and movies may also be used as part of laughter therapy to lower stress, pain, and fear.
- **Massage therapy** is a therapy that rubs, kneads, and/or touches muscles and soft tissues. It increases blood flow and may be used to lower pain and stress. Parents can be taught to give massages, or a massage therapist can give a massage. If your child bruises easily or has **peripheral neuropathy**, check with the doctor first. Learn more about [massage therapy](#).
- **Meditation** or prayer may help children to relax their minds and bodies, which can improve their overall sense of well-being. They may also lower stress, pain, anxiety, and depression and give your child a sense of hope, peace, and optimism. Learn more about [spirituality in cancer care](#).
- **Music therapy** is treatment that uses music to help relieve pain or stress and promote well-being. It is being studied in the treatment of several cancer-related problems and other conditions. Learn more about [music therapy](#).

## Questions to ask about practices that may help your child feel better

- How could this integrative medicine approach be used to help my child? \_\_\_\_\_  
\_\_\_\_\_
- Is this practice offered at this hospital? If not, where can my child go to receive it? \_\_\_\_\_  
\_\_\_\_\_
- Where can I go to learn more about this approach or practice? \_\_\_\_\_  
\_\_\_\_\_
- How much does it cost? Is the cost covered by my health insurance? \_\_\_\_\_  
\_\_\_\_\_

## Related resources

- [National Center for Complementary and Integrative Health](#)
- [Complementary and Alternative Medicine](#)

# Medical Tests and Procedures

This section has information about blood tests, scans, and other procedures. It also describes medicines that may help your child to relax or sleep during a procedure.



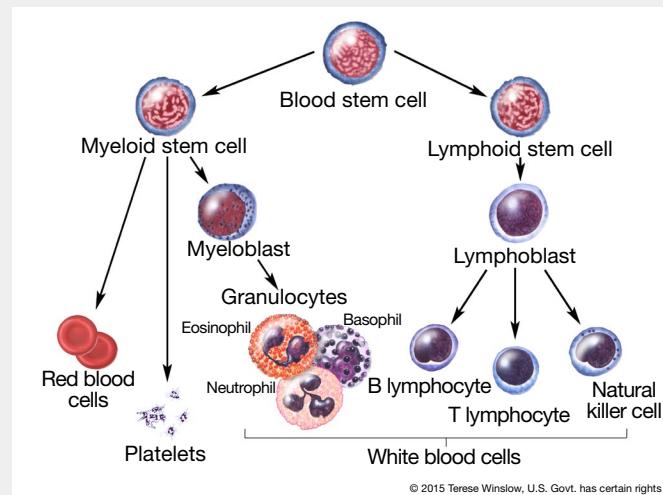
*"Blinky went everywhere with Sofia. Sometimes her child life specialist used Blinky as the patient to explain what would happen. Our daughter also liked telling Blinky about a procedure."*

## Blood tests

Blood tests are used to help diagnose conditions and monitor your child's health.

- A **blood chemistry study** measures the amounts of certain substances made in the body. A high or low level of a substance can be a sign of disease.
- A **CBC with differential** (also called blood cell count with differential) measures of the number of red blood cells, white blood cells, and platelets in the blood, including the different types of white blood cells. A CBC also measures the amount of **hemoglobin** (substance in the blood that carries oxygen) and the **hematocrit** (the amount of whole blood that is made up of red blood cells) to help diagnose and monitor many different conditions, including anemia and infection.
- A **peripheral blood smear** (also called a blood smear) gives information about the number and shape of different types of blood cells.

## Different types of blood cells



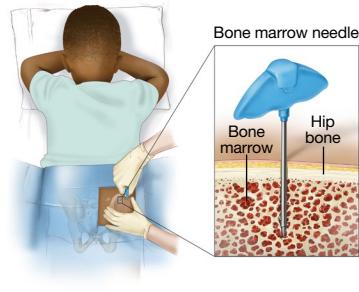
Bone marrow is the soft, sponge-like tissue in the center of most bones. It makes these types of cells:

- **Platelets** (also called thrombocytes) are tiny pieces of blood cells that help form blood clots or stop bleeding and help wounds to heal. When platelet counts are low, your child may bleed or bruise more easily.
- **Red blood cells** (also called RBC) contain a protein called **hemoglobin** that carries oxygen to all parts of the body. Low red blood cell levels may cause **anemia** and your child may be very tired, short of breath, and dizzy.
- **White blood cells** (also called WBC or leukocytes) help the body to fight off infection and diseases. Different types of white blood cells include **neutrophils**, **lymphocytes**, **monocytes**, **eosinophils**, and **basophils**. When white blood cell counts are low, it is hard for the body to fight infection.

- **Absolute neutrophil count** (also called ANC) measures the amount of a type of white blood cell called a neutrophil. When the neutrophil count is low the body's ability to fight bacterial infections is reduced. A low neutrophil count is called **neutropenia**.
- **Blood chemistry study** measures the amount of certain substances in the blood, such as sodium, potassium, fats, and proteins. An abnormal (high or low) amount of a substance can be a sign of disease or a side effect of treatment.

## Scans, tests, and procedures

These scans, tests, and procedures are used to make a diagnosis and to check your child's health:

| Why the test is done  | What to expect during the test   |
|---|--|
| An <b>angiogram</b> is a procedure that looks at blood vessels and the flow of blood.   | Your child will lie on an x-ray table or in a CT or MRI machine while an image is taken of the blood vessels and blood flow. A contrast dye is injected in the blood vessel to see if there are any blockages.   |
| A <b>biopsy</b> is a procedure to remove cells or tissues in order for a <b>pathologist</b> to study or perform other tests and to issue a <u><a href="#">pathology report</a></u> .  | <p>There are many different types of biopsy procedures. Common types of biopsies include:</p> <ul style="list-style-type: none"> <li>● an <b>incisional biopsy</b> removes only a sample of tissue</li> <li>● an <b>excisional biopsy</b> removes an entire lump or suspicious area</li> <li>● a <b>needle biopsy</b> removes a sample of tissue or fluid with a needle.</li> </ul> <p>Learn more about a <u><a href="#">biopsy</a></u>.</p>   |
| <b>Bone marrow aspiration</b> is a procedure in which a small sample of <b>bone marrow</b> (the soft, sponge-like tissue in the center of most bones that makes white blood cells, red blood cells, and platelets) is removed. The sample is usually taken from the hip bone, breastbone, or thigh bone and sent to a lab to be looked at under a microscope. It is used to diagnose some cancers, infections, and blood disorders. | <p>A small area of skin and the surface of the bone underneath will be numbed with an <b>anesthetic</b>. Then a special wide needle is inserted into the bone. A sample of liquid bone marrow is removed with a syringe attached to the needle.</p>  <p>This procedure may be done at the same time as a <b>bone marrow biopsy</b>. Learn more about <u><a href="#">bone marrow aspiration</a></u>.</p> |

A **bone scan** is a procedure that checks for abnormal areas or damage in the bones. It may be used to diagnose bone tumors or cancer that has spread to the bone. Bone scans may also be used to help diagnose fractures, bone infections, or other bone problems.

Before this test, a very small amount of radioactive material is injected into a vein and travels through the blood. The radioactive material collects in the bones and is detected by a **scanner** (instrument that takes pictures of the inside of the body).



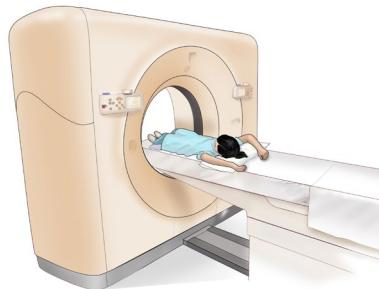
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Your child will lie still while a scanner moves above and below your child. The scanner does not touch your child. Learn more about a [bone scan](#).

A **CT scan** (also called CAT scan or computerized tomography) is a procedure that is used to make a series of detailed pictures of areas inside the body. It uses a computer linked to an x-ray machine. The pictures are taken from different angles and create 3-D views of tissues and organs. A CT scan may be used to help diagnose disease, plan treatment, or find out how well treatment is working.

Your child will lie on a table that slides into a donut shaped scanner. The CT machine moves back and forth, taking pictures. Sometimes a special dye is injected into a vein or swallowed to help organs or tissues show up more clearly.

Learn more about [computed tomography \(CT\) scans](#).



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An **MRI** (also called magnetic resonance imaging) is used to help visualize tumors and other tissue changes. It uses a powerful magnet and radio waves to create detailed pictures of organs and tissues. These pictures can show the difference between normal and diseased tissue. An MRI is especially useful for imaging the brain, the spine, the soft tissue of joints, and the inside of bones.

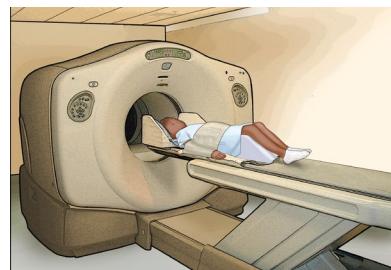
Your child will lie still on a table that is pushed into a long, round chamber. The MRI machine may make loud thumping noises and rhythmic beats. If your child is uncomfortable in closed spaces, ask if the hospital has an open MRI machine. Sometimes a special dye is injected into a vein to make any cancer cells show up brighter in the pictures. Learn more about [MRI scans](#).



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A **PET scan** (also called positron emission tomography scan) is a procedure used to make detailed computerized pictures of areas inside the body where glucose is taken up. Because cancer cells often take up more glucose than normal cells, the pictures can be used to find cancer cells in the body.

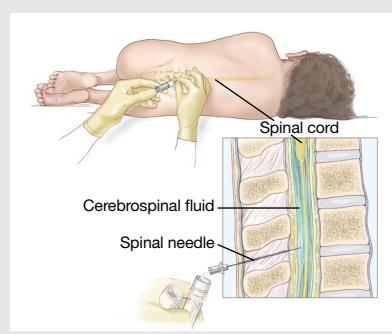
Before this test, a small amount of radioactive glucose is injected into a vein. During the procedure, your child will lie still on a table, which moves back and forth through a scanner that makes pictures. Learn more about a [PET scan](#).



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A **spinal tap** (also called a lumbar puncture) is a procedure in which a thin needle called a spinal needle is put into the lower part of the spinal column to collect **cerebrospinal fluid** for examination or to give drugs.

Your child will receive local anesthesia to numb the skin and an area on the lower back. During this test, your child will either lie curled up on their side or be seated and leaning over with their head on a pillow. Your child may have to lie flat for several hours after the test. This procedure may be painful for a short time. Learn more about [cerebral spinal fluid \(CSF\) collection](#).



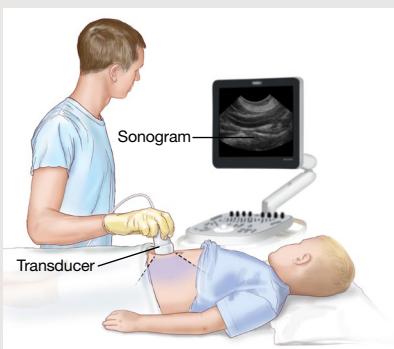
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A **tumor marker test** measures the amount of substances called tumor markers in tissue, blood, urine, or other body fluids. Tumor markers are made in higher amounts by cancer cells. This test may be used together with other tests to help diagnose cancer, plan treatment, find out how well treatment is working, or tell if cancer has come back.

A sample (such as a stool, blood, urine, or other bodily fluid or tissue, depending on the marker to be measured) will be taken and sent to a lab for testing. Learn more about [tumor markers](#).

An **ultrasound** is a procedure that uses high-energy sound waves to look at tissues and organs inside the body. The sound waves bounce off structures in the body, making echoes that a computer uses to form pictures of the tissues and organs on a computer screen (**sonogram**). During treatment for cancer it may be used to help make a diagnosis and to guide biopsies.

Your child will lie on a table while a technician slowly moves a wand, with warm clear gel on it, on the skin over the part of the body being examined. Learn more about [ultrasound](#).



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**X-ray** is a type of radiation used to make pictures of bones and other structures in the body.

A technician will position your child and direct the x-ray beam to the appropriate part of his body. Your child will need to stay very still and may need to hold his breath when the images are taken. Learn more about an [x-ray](#).

## Sedatives and anesthesia

Each child has unique needs based on their age and the type of procedure. Your child's health care team will talk with you about what is recommended for your child. Children may be given medicine (called a **sedative**) to help them relax, stay very still, or sleep during a procedure.

Sometimes a type of **anesthesia** may be given. Types of anesthesia include:

- **Local anesthesia** causes a loss of feeling in one small area of the body. It may be put on the skin to lessen pain, for example.
- **Regional anesthesia** causes a loss of feeling in one part of the body, such as an arm or leg.
- **General anesthesia** makes your child lose feeling and awareness. During general anesthesia, your child will be in a very deep sleep.

## Questions to ask about medical tests and procedures

- What test(s) or procedure(s) will my child have? \_\_\_\_\_  
\_\_\_\_\_
- What is the purpose of this test? \_\_\_\_\_  
\_\_\_\_\_
- Is there anything that my child needs to do to prepare? \_\_\_\_\_  
\_\_\_\_\_
- What will happen during the test? \_\_\_\_\_  
\_\_\_\_\_
- What will be done to help my child cope emotionally before and during the test? \_\_\_\_\_  
\_\_\_\_\_
- What are the risks? \_\_\_\_\_  
\_\_\_\_\_
- Where will the test be done? \_\_\_\_\_  
\_\_\_\_\_
- How long will it take? Will my child be awake during the test? \_\_\_\_\_  
\_\_\_\_\_
- Will it hurt? If so, how will pain be prevented or lowered? \_\_\_\_\_  
\_\_\_\_\_
- When will we know the results? \_\_\_\_\_  
\_\_\_\_\_

## Related resources

- [Understanding Laboratory Tests](#)
- [Anesthesia](#)
- [Blood](#)







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