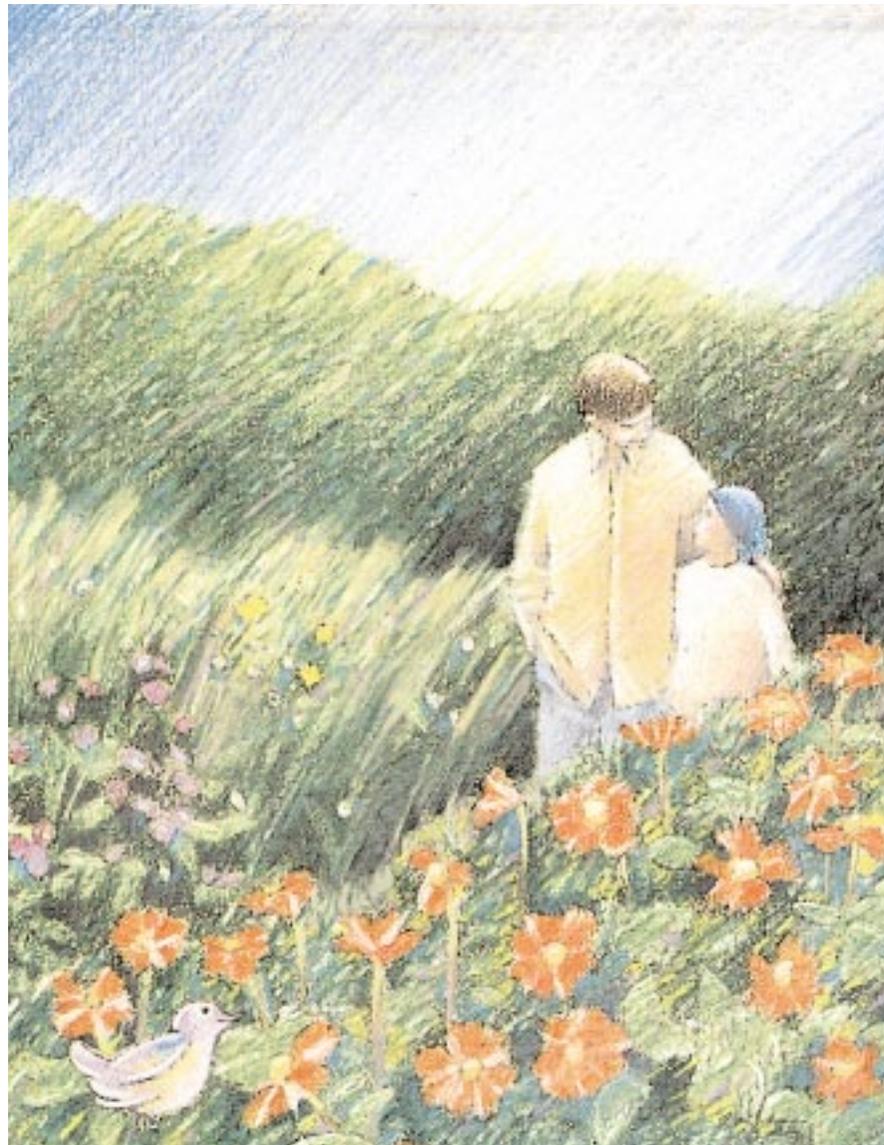


Young People With Cancer

A HANDBOOK FOR PARENTS



NATIONAL INSTITUTES OF HEALTH
National Cancer Institute

Young People With Cancer

A HANDBOOK FOR PARENTS



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health

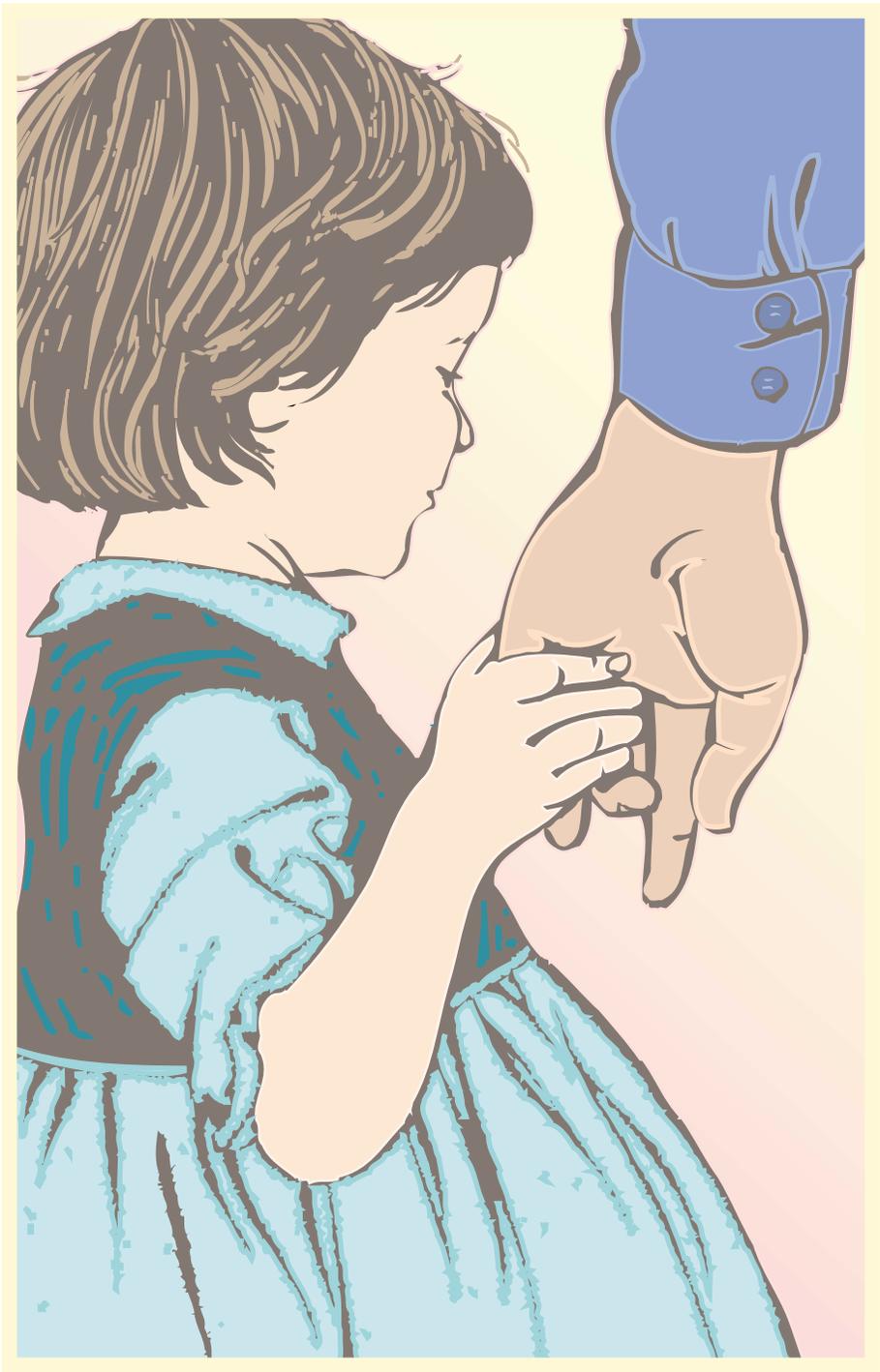
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Introduction

Young People with Cancer gives you information on all stages of your child's illness. It tells you what to expect and suggests ways to prepare for different situations. It can guide you to become your child's best advocate or supporter. You know your child better than anyone else—your child's personality, how your child copes with unknown situations and fear, what makes your child laugh or cry. You know what works best—how to humor and talk to your child and how to help your child relax. Try to remember that you are a key part of your child's treatment.

This booklet was reviewed by health professionals and, most important, by parents of children with cancer. Although this booklet does not tell you everything about cancer in children, it is a start, and it directs you to other sources of information. You may want to share this booklet with friends and relatives who want to learn more about what you and your child are going through. Use this booklet to learn:

- what cancer is and what the different kinds of cancer are
- how to find the best treatment
- about cancer treatment and side effects
- about common medical procedures
- how to talk to your child about cancer
- how to handle your own feelings, your child's feelings, and the feelings of others
- about common health issues
- what the future holds and
- where to get more information.

Because this booklet contains so much information, it may be useful to refer to the different sections as you need them. You can use the Table of Contents to find the sections of most interest to you. All the words in the dictionary are printed in **bold** the first time they appear in the text and are defined in the Dictionary beginning on page 103. The definitions are taken from the National Cancer Institute's CancerNet dictionary, which is available online at:

<http://www.cancernet.nci.nih.gov/dictionary.html>

More children than ever are surviving childhood cancer. Over the last 30 years, survival into adulthood increased from 30 percent to 80 percent. There are new and better drugs and methods to help children deal with the side effects of treatment. And children who have had cancer now have a better quality of life throughout childhood and into adulthood; fewer long-term ill effects follow the treatment.

Yet, in spite of all this good news, cancer is still a serious disease. You are not alone in facing your fears; help is available. A treatment team—doctors, radiation therapists, rehabilitation specialists, dietitians, **oncology nurses**, and social workers, among others—can help you and your child deal with the disease. They will also help ensure that your child gets the best treatment available with as few ill effects as possible. Resources such as this booklet provide information on childhood cancers and their treatment, suggestions on how to make your child as comfortable and as pain-free as possible, and advice on how to make time for family and friends.

What Is Cancer?

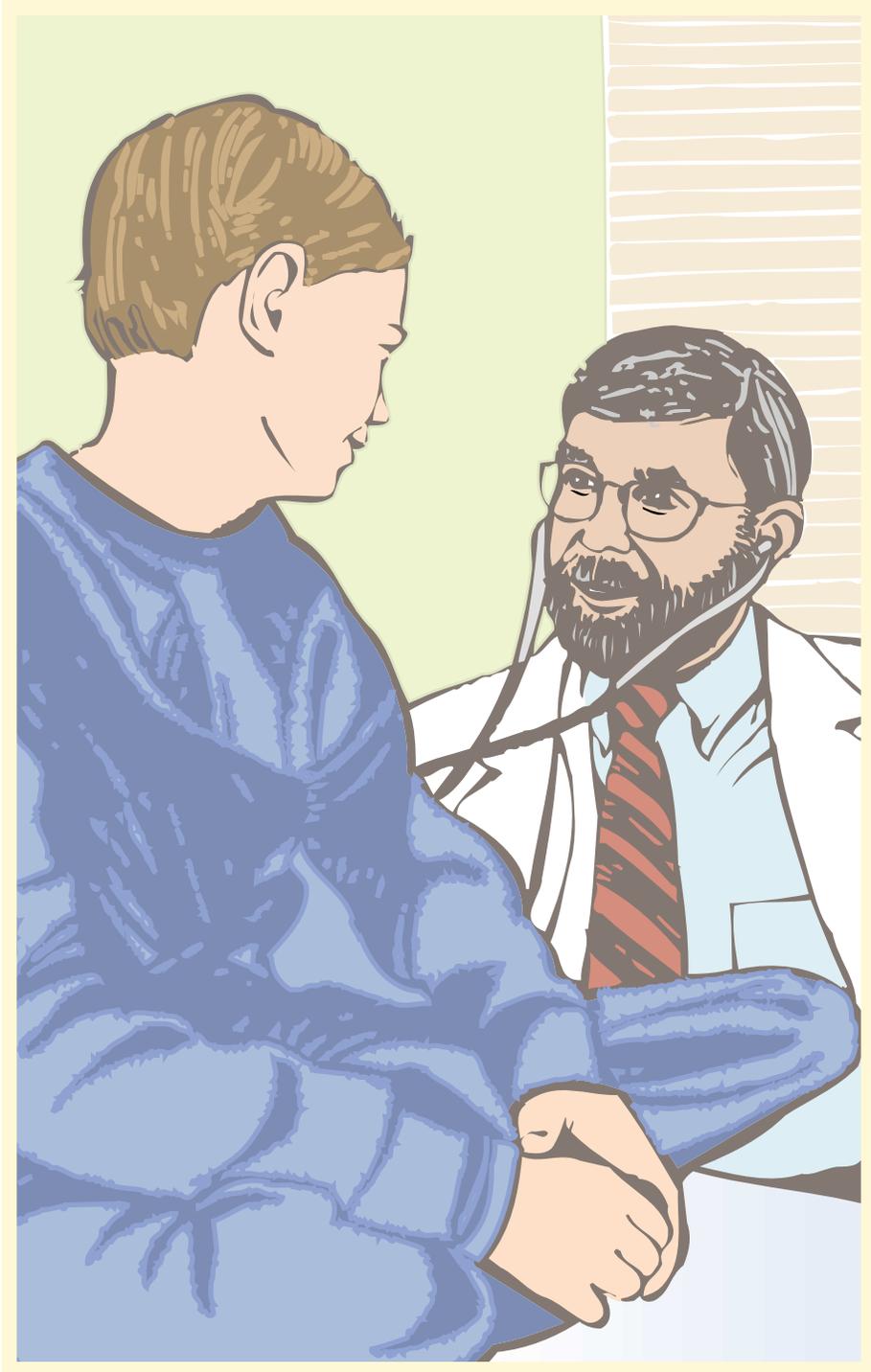
Cancer is a group of many related diseases that begin in cells, the body's basic unit of life. To understand cancer, it is helpful to know what happens when normal cells become cancerous.

The body is made up of many types of cells. Normally, cells grow and divide to produce more cells only when the body needs them. This orderly process helps keep the body healthy. Sometimes, however, cells keep dividing when new cells are not needed. These extra cells form a mass of tissue called a growth or **tumor**.

Tumors can be **benign** or **malignant**.

- **Benign** tumors are not cancer. They can often be removed and, in most cases, they do not come back. Cells from benign tumors do not spread to other parts of the body. Most important, benign tumors are rarely a threat to life.
- **Malignant** tumors are cancer. Cells in these tumors are abnormal and divide without control or order. They can invade and damage nearby tissues and organs. Also, cancer cells can break away from a malignant tumor and enter the bloodstream or the lymphatic system. That is how cancer spreads from the original cancer site to form new tumors in other organs. Cancer that has spread is called **metastatic cancer**.

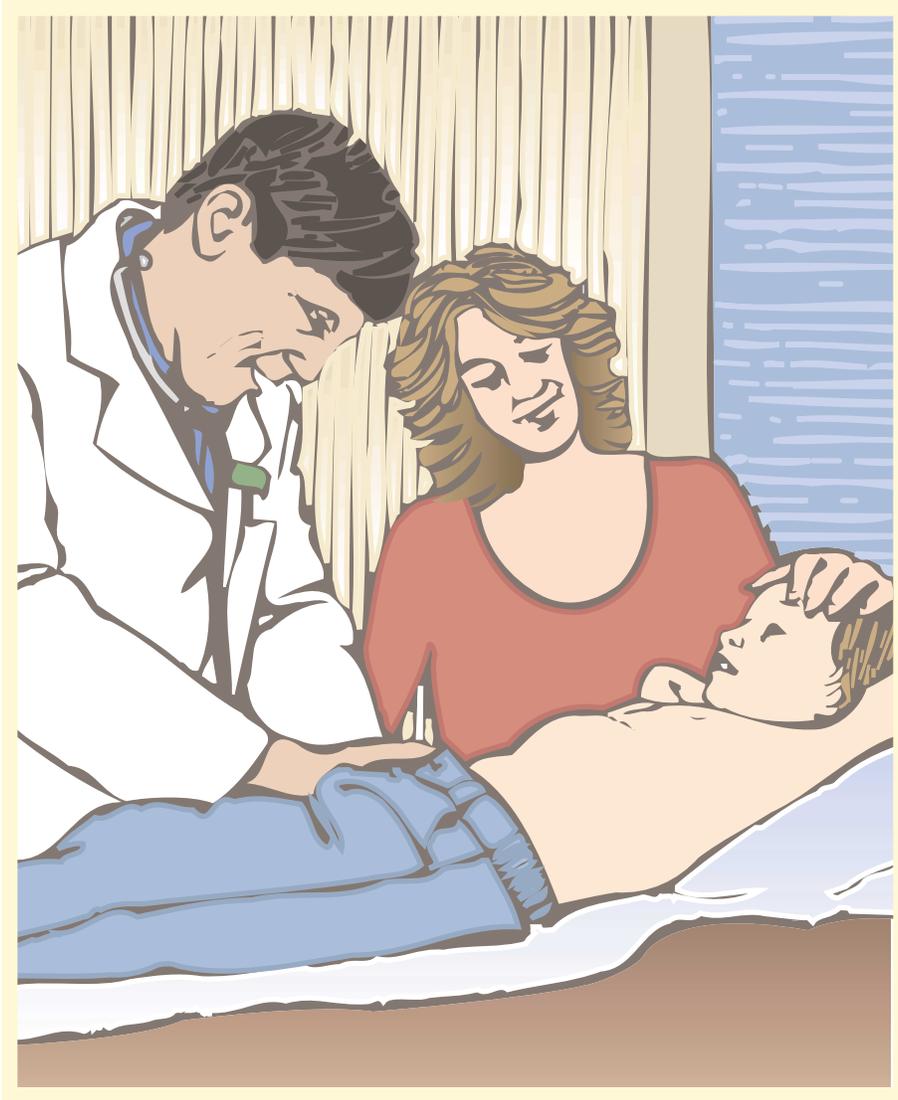
Most cancers are named for the organ or type of cell in which they begin. When cancer spreads (metastasizes), cancer cells are often found in nearby or regional **lymph nodes** (sometimes called lymph glands). If the cancer has reached these nodes, it means that cancer cells may have spread to other organs, such as the liver, bones, or brain. When cancer spreads from its original location to another part of the body, the new tumor has the same kind of abnormal cells and the same name as the primary tumor. For example, if lung cancer spreads to the brain, the cancer cells in the brain are actually lung cancer cells. The disease is called metastatic lung cancer (not brain cancer).



Children can get cancer in the same parts of the body as adults do, but some types of cancer are more common in children. The most common form of childhood cancer is **leukemia**. Leukemia is cancer of the blood. It develops in the **bone marrow**, which is a spongy substance that fills the inside of the bones and makes blood cells. Other cancers often found in children are brain tumors, childhood **lymphomas**, Hodgkin's disease, Wilms' tumors, neuroblastomas, osteogenic sarcomas, Ewing's sarcomas, retino-blastomas, rhabdomyosarcomas and hepatoblastomas. The Appendix contains information on the major types of childhood cancer.

Children's cancers do not always act like, get treated like, or respond like adult cancers. Avoid reading about adult cancer to learn about your child's prognosis. Childhood cancers can occur suddenly, without early symptoms, and have a high rate of cure.

You can find more details about these types of cancer in other National Cancer Institute (NCI) booklets. NCI's What You Need to Know About... brochures have information about specific types of cancer. (See page 96 for more information on available booklets.) To receive copies from the NCI-supported Cancer Information Service (CIS), call 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615. Also, many NCI publications may be viewed or ordered on the Internet at <http://cancer.gov/publications>.



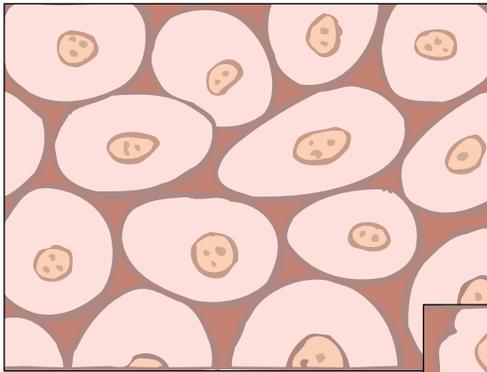
What Happens When Your Child Is Diagnosed With Cancer?

After your child's cancer has been diagnosed, a series of tests will be done to help identify your child's specific type of cancer. Called staging, this series of tests is sometimes done during diagnosis. Staging determines how much cancer is in the body and where it is located. To stage solid tumors, the doctor looks at the size of the tumor, the lymph nodes affected, and where it has spread. To stage leukemia, the doctor checks the bone marrow, liver, spleen, and lymph nodes around the sites where the leukemia can hide. Staging must be done to determine the best treatment. Many different tests can be used in staging, such as **x-rays, MRIs, CT (or CAT) scans**, and others. See pages 57-62 for a description of the various tests.

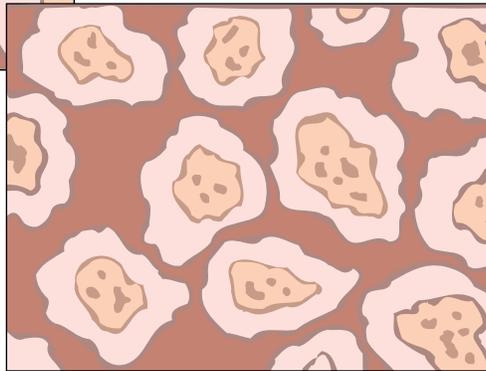
As soon as your child is suspected to have or is diagnosed with cancer, you will face decisions about who will treat your child, whom to ask for a second opinion (if desired or if the diagnosis is not clear), and what the best treatment is. After your child's staging is complete, the treatment team develops a plan that outlines the exact type of treatment, how often your child will receive treatment, and how long it will last.

Talking With Your Child's Doctor

Your child's doctor and the treatment team will give you a lot of details about the type of cancer and possible treatments. Ask your doctor to explain the treatment choices to you. It is important for you to become a partner with your treatment team in fighting your child's cancer. One way for you to be actively involved is by asking questions. You may find it hard to



Normal cells



Cancer cells

concentrate on what the doctor says, remember everything you want to ask, or remember the answers to your questions. Here are some tips for talking with those who treat your child:

- Write your questions in a notebook and take it to the appointment with you. Record the answers to your questions and other important information.
- Tape record your conversations with your child's health care providers.
- Ask a friend or relative to come with you to the appointment. The friend or relative can help you ask questions and remember the answers.

Questions to Ask the Doctor and Treatment Team

When your child's treatment team gives you information about your child's cancer, you may not remember everything. That is natural. It is a lot of information, and your emotions will get in the way as you try to take it all in. Use the three techniques listed above—write, tape record, and ask a friend for help—to help you retain the information you need to be an effective partner with your child's treatment team. Make sure you know the answers to these questions:

About the diagnosis—

- What kind of cancer does my child have?
- What is the stage, or extent, of the disease?
- Will any more tests be needed? Will they be painful? How often will they be done?

About treatment choices—

- What are the treatment choices? Which do you recommend for my child? Why?
- Would a clinical trial (carefully designed studies that test new kinds of treatments) be right for my child? Why?
- Have you treated other children with this type of cancer? How many?
- What are the chances that the treatment will work?
- Where is the best place for my child to receive treatment? Are there specialists—such as surgeons, radiologists, nurses, anesthesiologists, and others— trained in pediatrics? Can my child have some or all of the treatment in our home town?

About the treatment—

- How long will the treatment last?
- What will be the treatment schedule?
- Whom should we ask about the details of financial matters?

(continued on next page)

Questions to Ask Your Doctor and Treatment Team

(continued from previous page)

- Will the treatment disrupt my child's school schedule?

About side effects—

- What possible side effects of the treatment can occur, both right away and later?
- What can be done to help if side effects occur?

About the treatment location—

- How long will my child be in the hospital?
- Can any treatment be done at home? Will we need any special equipment?
- Does the hospital have a place where I can stay overnight during my child's treatment?

About school and other activities—

- Is there a child-life worker specialist (a professional who is responsible for making the hospital and treatment experience less scary for the child) to plan play therapy, schoolwork, and other activities?
- When can my child go back to school?
- Are there certain diseases my child cannot be around? Should I have my child and his or her siblings immunized against any diseases?
- Will my child need tutoring?
- Is information available to give to the school system about my child's needs as he or she receives treatment?

How Can My Child Get the Best Treatment?

Before your child starts treatment, make sure you feel comfortable with your choice of the doctor and hospital to treat your child's cancer.

Who Should Treat My Child?

It is best for your child to be treated by a health care provider who specializes in the diagnosis and treatment of children's cancers—a pediatric **oncologist**.

Once you have chosen a doctor and discussed a diagnosis and treatment plan, but before treatment has started, you may want to get a second opinion—that is, you may want to ask a different doctor to review the diagnosis and plan. Some insurance companies require a second opinion; some may pay for it if you ask. A second opinion may also be obtained during the course of treatment if it is not working as hoped. Most doctors support a parent's decision to get a second opinion and many even suggest you do so. To find specialists to get a second opinion, you might—

- Ask your child's doctor to suggest a specialist for a second opinion.
- Get the names of doctors who specialize in treating childhood cancer from the local medical society, a nearby hospital, or a medical school. You can find the telephone numbers for these organizations in your telephone directory or the Yellow Pages.
- Contact an NCI Comprehensive Cancer Center for a second opinion and possible treatment. Considered "Centers of Excellence," these cancer centers' programs have been reviewed and selected by NCI. They offer the most up-to-date diagnosis and treatment of cancer and are devoted to both basic and clinical research. To obtain information about the location of the different cancer centers, call the CIS at 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615.



- Contact the Pediatric Oncology Branch, NCI, located in Bethesda, Maryland, to ask for a second opinion appointment. They can be reached at 1-877-624-4878.

What Is a Standard Therapy Versus a Clinical Trial?

Your child's doctor may recommend a **standard therapy** or a clinical trial. Standard therapy is the best treatment available outside of clinical trials for a specific type and stage of cancer.

A cancer clinical trial is a research study. In a clinical trial, a new treatment is used with a group of patients to find out:

- if it is safe
- if it destroys the cancer

- if it has side effects and how severe they might be
- if it is better than standard therapy.

These new treatments are first tested in the laboratory and on animals. If a treatment shows promise of being better than the standard therapy, it is tested with patients in a clinical trial.

Most clinical trials are carried out in steps called phases. Each phase answers different questions about the treatment. Patients may be eligible for studies in different phases, depending on their general condition and the type and stage of their cancer.

- **Phase I studies** test new treatments in humans to determine if the treatment can be given safely and if it has harmful side effects. Researchers look for the best dose and the best way to deliver the treatment. Because less is known about the possible risks and benefits in Phase I, these studies usually include only a limited number of patients who would not be helped by other treatments.
- **Phase II studies** focus on learning whether the new treatment actually has an anticancer effect. As in Phase I, only a small number of people take part because of the risks and unknowns involved.
- **Phase III studies** compare the results of people receiving the new treatment with results of people receiving standard therapy. In most cases, studies move into Phase III testing only after a treatment shows promise in Phases I and II. Phase III studies may include hundreds of people around the country.
- **Phase IV studies** evaluate the side effects of the new treatment—once it has been approved and is being marketed—that were not apparent in the Phase III trial. Thousands of people are involved in a Phase IV trial.

Clinical trials have played an important role in producing new and better treatments. About two-thirds of children with cancer are treated in clinical trials.

You and your child's doctor can learn about clinical trials from PDQ[®]—NCI's cancer information database. PDQ[®] contains:

- descriptions of current clinical trials, including information about the purpose of the study, who is eligible for the study, details of the treatment program, and the names and addresses of doctors and places conducting the study
- the latest treatment information for most types of cancer (also available by fax at 1-800-624-2511 or 301-402-5874)

You may ask your doctor to obtain information from PDQ[®], or you may call the NCI-supported Cancer Information Service (CIS) at 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615 to ask for a PDQ[®] search. Read more about PDQ[®] on the NCI CancerNet Web site at <http://cancer.net.nci.nih.gov/trials.html>. To find out about NCI trials taking place on the main campus of the National Institutes of Health in Bethesda, Maryland, you may also call the NCI's Pediatric Oncology Branch at 1-877-624-4878.

Where Should My Child Be Treated?

Once the treatment is planned, you will need to decide where your child will be treated. Treating children is different from treating adults. Whenever possible, it is best for your child to begin treatment at a hospital or treatment center where many children have been treated for cancer. Selecting a hospital and staff specializing in treating childhood cancer will help your child receive the best available treatment right from the beginning. To obtain information about hospitals and treatment centers that specialize in treating childhood cancer, call the CIS at 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615.

How Do You Talk With Your Child About Cancer?

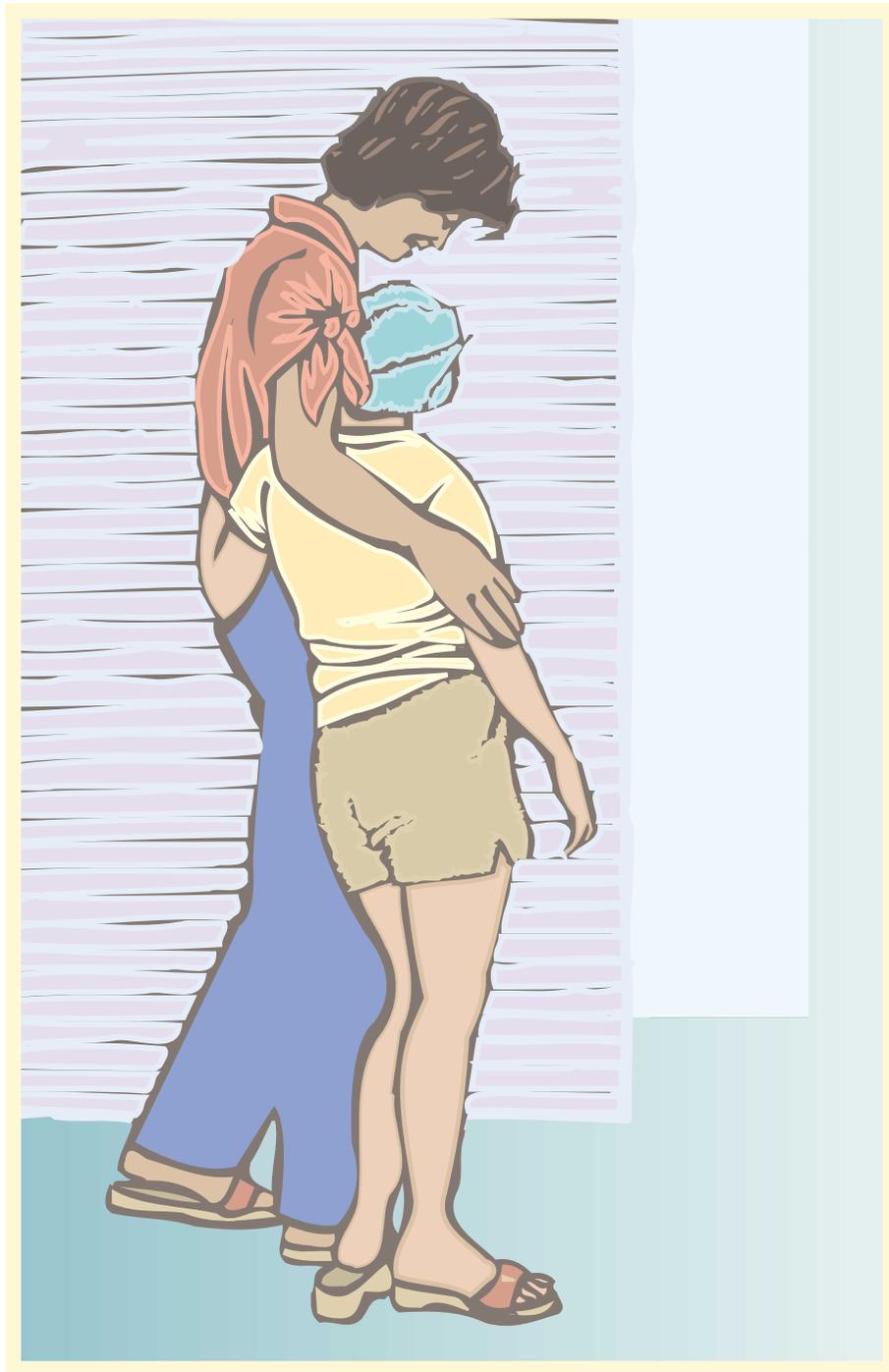
Your first question may be, “Should I tell my child about the cancer?” You may want to protect your child, but children usually know when something is wrong. Your child may not be feeling well, may be seeing the doctor often, and may have already had some tests. Your child may notice that you are afraid. No matter how hard you try to keep information about the illness and treatment from your child, others—such as family, friends, and clinic or hospital staff—may inadvertently say things that let your child know about the cancer. In addition, it will upset your child to find out that you were not telling the truth; your child depends on you for honest answers.

Why Should I Tell My Child?

Telling your child about his or her cancer is a personal matter, and family, cultural, or religious beliefs will come into play. It is important to be open and honest with your child because children who are not told about their illness often imagine things that are not true. For example, a child may think he or she has cancer as punishment for doing something wrong. Health professionals generally agree that telling children the truth about their illness leads to less stress and guilt. Children who know the truth are also more likely to cooperate with treatment. Finally, talking about cancer often helps to bring the family closer together and makes dealing with the cancer a little easier for everyone.

What Questions Do Parents Have?

Parents have many questions about talking with their children about the diagnosis. Perhaps you have asked some of these yourself.



When Should My Child Be Told?

Because you are probably the best judge of your child's personality and moods, you are the best person to decide when your child should be told. Keep in mind, though, that your child is likely to know early on that something is wrong, so you may want to tell your child soon after the diagnosis. In fact, most parents say it is easiest to tell them then. Waiting days or weeks may give your child time to imagine worse things than the truth and develop fears that may be hard to dispel later. Certainly, it would be easier for your child if he or she is told before treatment starts.

Who Should Tell My Child?

The answer to this question is personal. As a parent, you may feel that it is best for you to tell your child. Some parents, however, find it too painful to do so. Other family members or the treatment team—doctor, nurse, or social worker—may be able to help you. They may either tell your child for you or help you explain the illness.

Thinking about what you are going to say and how to say it will help you feel more relaxed. But how do you decide just what to say? Family and close friends, members of the treatment team, parents of other children who have cancer, members of support groups (you can find information about them at the end of this booklet), and clergy members can offer ideas.

Who Should Be There?

Your child needs love and support when hearing the diagnosis. Even if the doctor explains the illness, someone your child trusts and depends upon should be present. Having the support of other family members at this time can be very helpful.

What Should My Child Be Told?

How much information and the best way to relate this information depends on your child's age and what your child can understand. Being gentle, open, and honest is usually best.

The following sections describe what most children in various age groups are likely to understand. These guidelines are general; each child is different. Your child may fit into more than one or none of these categories.

■ Up to 2 Years Old

Children this young do not understand cancer. They understand what they can see and touch. Their biggest concern is what is happening to them right now. They worry most about being away from their parents.

After children are a year old, they think about how things feel and how to control things around them. Very young children are most afraid of medical tests. Many cry, run away, or squirm to try to control what is happening.

Because children begin to think about and understand what is going on around them at about 18 months, it is best to be honest. Be truthful about trips to the hospital and explain procedures that may hurt. You can tell your child that needlesticks will hurt a minute and that it is okay to cry. Being honest lets your child know that you understand and accept his or her feelings and helps your child trust you.

When you can, give your child choices. For example, if a medicine is taken by mouth, you might ask if your child would like it mixed in apple juice, grape juice, or applesauce.

■ 2 to 7 Years Old

When children are between the ages of 2 and 7, they link events to one thing. For example, they usually tie illness to a specific event such as staying in bed or eating chicken soup. Children this age often think their illness is caused by a specific action. Therefore, getting better will “just happen” or will come if they follow a set of rules.

These approaches might help when talking with a child in this age group:



- Explain that treatment is needed so the hurting will go away or so the child can get better and play without getting so tired.
- Explain that the illness or treatment is not punishment for something the child has done, said, or thought.
- Be honest when you explain tests and treatments. Remind the child that all of these things are being done to get rid of the cancer and to help him or her get well.
- Use simple ways to explain the illness. For example, try talking about the cancer as a contest between “good” cells and “bad” cells. Having treatment will help the good cells to be stronger so that they can beat the bad cells.

■ 7 to 12 Years Old

Children ages 7 to 12 are starting to understand links between things and events. For example, a child this age sees his or her illness as a set of symptoms, is less likely to believe that something he or she did caused the illness, understands that getting better comes from taking medicines and doing what the doctor says, and is able to cooperate with treatment.

You can give more details when explaining cancer, but you should still use situations your child may be used to. You might say that the body is made of up different types of cells, and these cells have different jobs to do. Like people, these cells must work together to get the job done. You might describe the cancer cells as “troublemakers” that get in the way of the work of the good cells. Treatment helps to get rid of the troublemakers so that other cells can work well together.

■ 12 Years and Older

Children over 12 years old can often understand complicated relationships between events. They can think about things that have not happened to them. Teenagers tend to think of illness in terms of specific symptoms, such as tiredness, and in terms of limits or changes in their everyday activity. But because they also can understand the reason for their symptoms, you can explain cancer as a disease in which a few cells in the body go “haywire.” These “haywire” cells grow more quickly than normal cells, invade other parts of the body, and get in the way of how the body usually works. The goal of treatment is to kill the “haywire” cells. The body can then work normally again, and the symptoms will go away.

What Are Some Questions That Your Child May Ask?

Children are naturally curious about their disease and have many questions about cancer and cancer treatment. Your child will expect you to have answers to most questions. Children may begin to ask questions right after diagnosis or may wait until later. Here are some common questions and some ideas to help you answer them.

Why Me?

A child, like an adult, wonders “Why did I get cancer?” A child may feel that it is his or her fault, that somehow he or she caused the illness. Make it clear that not even the doctors know exactly what caused the cancer. Neither you, your child, nor his or her brothers or sisters did, said, or thought anything that caused the cancer. Stress also that cancer is not contagious, and your child did not “catch” it from someone else.

Will I Get Well?

Children often know about family members or friends who died of cancer. As a result, many children are afraid to ask if they will get well because they fear that the answer will be “no.” Thus, you might tell your child that cancer is a serious disease, but that treatment—such as medicine, radiation, or an operation—has helped get rid of cancer in other children, and the doctors and nurses are trying their best to cure your child’s cancer, too. Knowing that caring people—such as family, doctors, nurses, counselors, and others—surround your child and your family may also help him or her feel more secure.

What Will Happen to Me?

When your child is first diagnosed with cancer, many new and scary things will happen. While at the doctor’s office, hospital, or clinic, your child may see or play with other children with cancer who may not be feeling well, have lost their hair, or have had limbs removed because of cancer. Your child may wonder, “Will these things happen to me?” Yet, your child may be too afraid to ask questions. It is important to try to get your child to talk about these concerns. Explain ahead of time about the cancer, treatment, and possible side effects. Discuss what the doctor will do to help if side effects occur. You can also explain that there are many different types of cancer and that even when two children have the same cancer, what happens to one child will not always happen to the other.

Children should be told about any changes in their treatment schedule or in the type of treatment they receive. This information helps them prepare for visits to the doctor or hospital. You may want to help your child keep a calendar that shows the days for doctor visits, treatments, or tests. Do not tell younger children about upcoming treatments far ahead of time if it makes them nervous.

Why Do I Have to Take Medicine When I Feel Okay?

With cancer, your child may feel fine much of the time but need to take medicine often. Children do not understand why they have to take medicine when they feel well. You may want to remind your child of the reason for taking the medicine in the first place. For example, a child could be told: “Although you are feeling well, the bad cells are hiding. You must take the medicine for a while longer to find the bad cells and stop them from coming back.”

What About Treatment?

To plan the best treatment, the doctor and treatment team will look at your child's general health, type of cancer, stage of the disease, age, and many other factors. Based on this information, the doctor will prepare a treatment plan that outlines the exact type of treatment, how often your child will receive treatment, and how long it will last. Each child with cancer has a treatment plan that is chosen just for that child; even children with the same type of cancer may receive different treatments. Depending on how your child responds to treatment, the doctor may decide to change the treatment plan or choose another plan.

Before treatment begins, your child's doctor will discuss the treatment plan with you, including the benefits, risks, and side effects. Then you and the treatment team will need to talk with your child about the treatment. After the doctor fully explains the treatment and answers your questions, you will be asked to give your written consent to go ahead with treatment. Depending on your child's age and hospital policy, your child may also be asked to give consent before treatment.

The treatment plan may seem complicated at first. But the doctor and treatment team will explain each step, and you and your child will soon become used to the routine. Many parents find it helpful to get a copy of the treatment plan to refer to as the treatment proceeds. It also helps them in arranging their own schedules. Do not be afraid to ask questions or speak up if you feel something is not going right. Your child's doctor is often the best person to answer your questions, but other members of the treatment team can give you information, too. If you feel as though you need extra time with the doctor, schedule a meeting or phone call. Remember, you are part of the treatment team and should be involved in your child's treatment.



What Are the Different Types of Cancer Treatment?

The types of treatment used most often to treat cancer are **surgery, chemotherapy, radiation therapy, immunotherapy, and bone marrow or peripheral blood stem cell transplantation**. Doctors use these treatments to destroy cancer cells. Depending on the type of cancer, children may have one kind of treatment or a combination of treatments. Most children receive a combination of treatments, called **combination therapy**.

Treatments for cancer often cause unwanted or unpleasant side effects such as nausea, hair loss, and diarrhea. Side effects occur because cancer treatment that kills cancer cells can hurt some normal cells, too. As your child begins treatment, you may want to keep the following in mind.

- The kinds of side effects and how bad they will be depend on the kind of drug, the dosage, and the way your child's body reacts.
- The doctor plans treatment so that your child has as few side effects as possible.
- The doctor and treatment team have ways to lessen your child's side effects. Talk with them about things that can be done before, during, and after treatment to make your child comfortable.
- Lowering the treatment dosage slightly to eliminate unpleasant side effects usually will not make the treatment less able to destroy cancer cells or hurt your child's chances of recovery.
- Most side effects go away soon after treatment ends.

Remember that not every child gets every side effect, and some children get few, if any. Also, how serious the side effects are varies from child to child, even among children who are receiving the same treatment. The doctor or treatment team can tell you which, if any, side effects your child is likely to have and how to handle them. If you know what side effects can occur, you can recognize them early.

Surgery

For many solid tumors, surgery is an essential part of the treatment. Surgery is a local therapy to remove the tumor. Tissue around the tumor and nearby lymph nodes may also be removed during the operation. Sometimes radiation or chemotherapy is used first to shrink the tumor before it is removed. Shrinking the tumor makes the surgery easier.

Helping Your Child Face Fears About Surgery

Your child is likely to have many worries about surgery. Your child may ask:

- What is it like to be put to sleep?
- Will I feel a lot of pain?
- Will my body be changed?
- How will I feel about my body after the operation?
- Will my parents be with me when I wake up?

Here are some suggestions that might help your child face surgery:

- **Give honest answers to your child's questions.** Your child may lose trust in you if what you say does not match what really happens. Your child needs to trust you.
- **Learn as much as you can about your child's operation.** To give the correct answers to your child's questions, you will need to find out as much as possible about what will happen. The doctors and other members of the treatment team can give you the facts you need to prepare your child.
- **Visit the operating and recovery rooms before the surgery.** To help children get ready for surgery, many hospitals encourage them to visit the rooms where they will be during surgery and recovery. They can meet and talk with the people who will be there. For instance, young children may be shown a surgical mask and given one to try on or to put on a toy or another person.

■ **Talk with your child about feelings and concerns.**

Above all, try to get your child to talk about any feelings or concerns he or she has about the surgery.

Possible Side Effects of Surgery

Side effects from surgery depend on the location of the tumor, the type of operation, the child's general health, and other factors. Common side effects include pain, headaches, nausea, and constipation. These effects may be from the surgery, pain medicine, or lack of exercise. The doctor will give your child medicine, as needed, to help ease these side effects and other symptoms.

Children and Amputations

In the past, amputations were often necessary to remove bone tumors in the arms and legs. Depending on the type of tumor, however, doctors more and more can use procedures that spare the limb and make amputation unnecessary. Fewer children suffer the loss of a limb. Your child's treatment team will explain the options available to you.

For some children, however, amputation remains the best choice. These children have special concerns. They wonder what it will be like not to have an arm or leg. Will they be able to do everyday things? How will they do them? How will others act toward them? They may feel a lack of wholeness after surgery. Sometimes it is more difficult for parents than for children to adjust to an amputation. Generally, younger children adjust more quickly. Adolescents have special concerns. They may be more sensitive about the way they look to others. They also may worry about how the amputation will affect developing and keeping relationships, participating in sports activities, getting married, and having children.

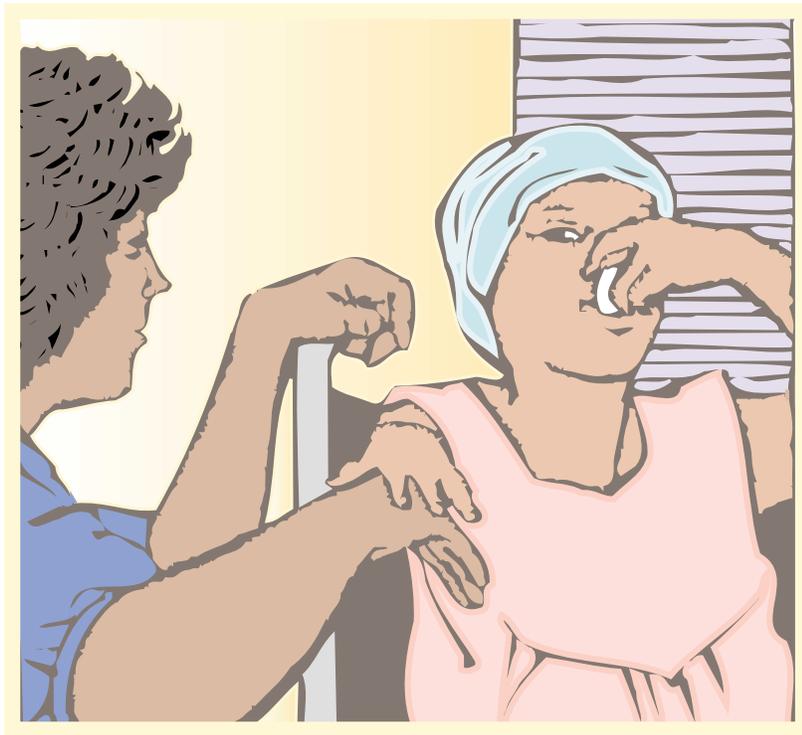
It may be helpful for your child to see how others have adjusted to an amputation. Meeting other children who have had amputations and who are doing well can be very helpful. Your child will learn that he or she can have a full and active life—most children can participate in the same activities they did before having an amputation. They can still walk, run, ride a bicycle, ski, swim, and even mountain-climb. It may also help for the

treatment team to show your child an artificial limb, or **prosthesis**, and other devices or aids that will help with movement.

After surgery, your child will be aware of a bulky dressing or bandage at the site of the surgery. Your child may feel “phantom pain,” an eerie but common feeling. Sensations such as cold, itching, and pain are felt in the limb as if it were still part of the body. Doctors do not know what causes phantom pain. The best explanation is that the brain has been accustomed to receiving messages from the nerves in the limb that has been amputated. It takes time for the brain to get used to the nerve fibers that remain and the new messages from the stump. Sometimes a light massage and changing the position of the stump will offer some relief. The doctor will usually start medication ahead of time to ease your child’s pain and can also order some medicine to treat the phantom pain when it happens.

As part of the rehabilitation, a physical therapist will help your child with exercises to strengthen the muscles needed to support a temporary prosthesis. These exercises are often hard and can be painful, so your child needs to be encouraged and supported during this time. Once the muscles become stronger, the doctor may order a temporary prosthesis for your child. The prosthesis is made by a **prosthetist**, a person skilled in making artificial limbs. The temporary prosthesis will be bulkier and heavier than the permanent one. The way it looks may be disappointing, but the added heaviness will further strengthen the stump and the bulkiness will protect it. Once the stump is fully healed, and your child is able to move the limb well with the temporary prosthesis, fitting for the permanent prosthesis will begin.

Health professionals will be available to help your child and family throughout the entire process—from making treatment choices to adjusting to the permanent prosthesis. Drawing upon the strength and comfort of family members and joining a support group may also help you cope.



Chemotherapy

Chemotherapy is the use of “anticancer drugs” to treat cancer. Chemotherapy is systemic therapy, which means that the drugs flow through the bloodstream to nearly every part of the body to kill cancer cells wherever they may be. Because some anticancer drugs work better together than alone, chemotherapy may consist of more than one drug. This approach is called combination chemotherapy.

Depending on the type of cancer your child has and which drugs are used, chemotherapy may be given in one or more of these ways:

- **By mouth (oral medication)**—The drugs are swallowed in liquid or pill form. If your child has trouble swallowing pills, you can break the pills into smaller pieces, or you

may crush and mix them with applesauce, jam, pudding, or other food that your child likes.

- **Intravenously (IV)**—The drugs are injected by needle into a vein or into an IV line.
- **Intramuscular injection (IM)**—The drugs are injected by needle into the muscle. Your child will know it as a “shot.”
- **Subcutaneous injection (SC)**—The drugs are injected by needle just below the skin. Your child will also know this as a “shot.”
- **Intrathecal injection (IT)**—The drugs are injected by needle into the spinal fluid.

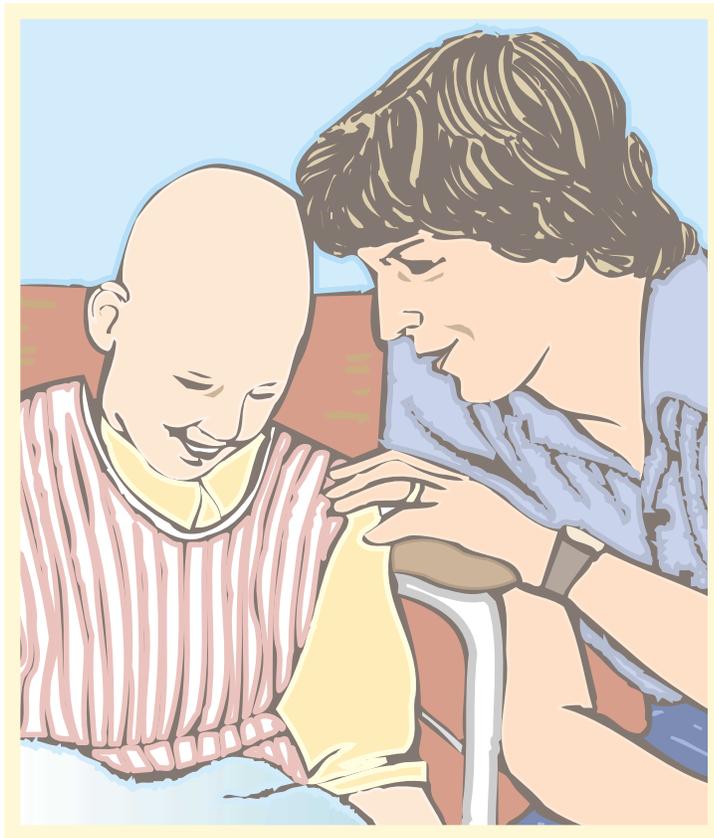
Although your child may be able to receive chemotherapy treatments at home, he or she will probably need to go to the hospital or doctor’s office to receive IV drugs or injections. Depending on the medicine, your child may need to stay in the hospital, perhaps overnight or longer.

Oral Chemotherapy

When possible, involve your child in this treatment. For example, you may want to keep a special calendar to help your child track when medicine should be taken. Older children, particularly adolescents, may want to be responsible for taking and keeping track of their medication. Even so, you still need to make sure that the medicine is being taken as ordered. Be sure to notify the doctor if your child misses any doses of medication or if he or she vomits them up.

Intravenous Chemotherapy

Your child will get the drug through a thin needle put into a vein, usually on the hand or in the arm. In babies and very small children, the needle may be placed in a vein in the scalp. Although getting chemotherapy usually does not hurt, it may be painful when the IV needle is put in, and the drugs may cause a burning feeling. If the drug leaks from the vein, it may burn the skin, so care must be taken to make sure the IV line is firmly in



place. The nurse or doctor must act right away if the needle comes out of the vein.

Another way to give IV chemotherapy is through a **catheter**, a thin plastic tube placed into a large vein in the body. The catheter remains in place during the course of treatment so that drugs can be given without having to place a needle into the vein over and over again. The most commonly used are central venous catheters. While the child is under general or local anesthesia, the catheter is usually put into a large vein in the chest by making a small incision (cut) near the collarbone. Two types of central venous catheters are commonly used.

- One type of catheter is an external venous catheter (for example, a Broviac or Hickman catheter). In this type of catheter, the plastic tube extends outside the body.

- The second type (for example, a Port-a-Cath catheter) is placed under the skin and needs to have a needle placed into it each time it is used. This type of catheter may be more appealing to adolescents or for families who cannot take care of a catheter that needs special daily care.

In addition to chemotherapy, pain medicine and blood transfusions can be given through the catheter, and blood can be drawn from the body through the catheter.

Side Effects of Chemotherapy

Side effects can occur when the anticancer drugs affect not only the cancer cells but healthy cells as well. Different drugs produce different side effects. Ask your doctor or nurse what side effects your child is most likely to have and when they are likely to occur. Side effects are either acute (they happen right away) or delayed (they happen days, weeks, or years after chemotherapy). The most common side effects of chemotherapy are listed in the following chart.

You may also find these NCI materials useful:

- *Chemotherapy and You: A Guide to Self-Help During Treatment* discusses side effects from chemotherapy and ways to cope with them
- *Eating Hints for Cancer Patients* provides suggestions for how to eat well during cancer treatment.

You can receive copies from the NCI-supported Cancer Information Service (CIS) by calling 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615. Also, many NCI publications may be viewed or ordered on the Internet at <http://cancer.gov/publications>.

Side Effects of Chemotherapy

Side Effect

What You Can Do

DIGESTIVE TRACT PROBLEMS

Nausea and vomiting

- Ask your child's doctor about medicines to control nausea and vomiting and/or sedatives to help your child sleep through nausea.
- Ask your doctor if it is alright to give your child milk or antacids before taking oral anticancer drugs. Certain oral anticancer drugs should not be taken with milk.
- Feed your child light foods 3–4 hours before treatment.
- Encourage your child to eat small amounts of food often and slowly.
- Avoid serving sweet, greasy, and spicy foods or foods that have strong odors.
- Serve your child cold meals, such as sandwiches, instead of hot foods.
- Encourage your child to take liquids first, and then wait 30–60 minutes before eating solids. Most children tolerate liquids better than solids.
- Have your child rest after meals.
- If your child is vomiting, do not give anything to eat or drink until it is under control. Once the vomiting is under control, give small amounts of clear liquids (for example, water, broth, milk-free ices, and gelatin desserts). Begin with 1 teaspoon every 10 minutes; gradually increase the amount to 1 tablespoon every 20 minutes; and, finally, try 2 tablespoonfuls every 30 minutes. When your child can keep down clear liquids, try denser liquids (for example, strained cereal, pudding,

Side Effects of Chemotherapy (continued)

Side Effect	What You Can Do
DIGESTIVE TRACT PROBLEMS (continued)	
Nausea and vomiting <i>(continued)</i>	yogurt, milkshakes, cream soups). Give small amounts as often as your child can keep them down. Gradually work up to solid foods.
Diarrhea	<ul style="list-style-type: none"> • Contact your doctor if your child's diarrhea is severe; that is, more than three loose stools per day. • Avoid giving your child fatty foods. • Try serving foods that are high in proteins and calories but low in fiber, such as plain or vanilla yogurt, rice with broth, or noodles. • Serve your child foods and liquids that are high in sodium and potassium. Foods high in potassium that do not cause diarrhea are bananas, peach and apricot juices, and boiled or mashed potatoes.
Constipation	<ul style="list-style-type: none"> • Call your doctor if your child goes more than 2 days without having a bowel movement. • Encourage your child to drink more fluids, such as apple juice. • Make sure your child gets some exercise. • Serve your child high-fiber foods, such as wholegrain breads and cereals; brown rice; dried fruits, such as raisins and prunes; and raw fresh vegetables.
Heartburn or stomach ache	<ul style="list-style-type: none"> • Ask your child's doctor about giving your child an antacid. • Avoid serving your child fried or greasy very spicy.

Side Effects of Chemotherapy (continued)

Side Effect

What You Can Do

MOUTH PROBLEMS

Sore mouth or throat, mouth sores

- Ask your child's doctor for medicine (sprays, special mouthwashes, and lozenges) for your child's mouth.
- Give your child a sponge toothbrush or cotton swab to brush his or her teeth.
- Have your child rinse his or her mouth every 2–3 hours and after meals, using baking soda solution or water.
- Avoid serving very cold, hot, spicy, or acidic foods.
- Try serving soft foods.
- Contact your child's doctor if your child has mouth sores, painful areas, or patches of red or white in the mouth.

Change in taste—foods have less taste or a bitter metallic taste

Try well-seasoned foods or tart foods such as oranges, lemonade, or lemon tart. (Do not try these foods if your child has a sore mouth, throat, or gums.) Pizza and taco chips frequently become children's favorite foods.

SKIN AND HAIR PROBLEMS

Hair loss

- Use a mild shampoo.
- Cut your child's hair short.
- Avoid using hair dryers and electric curlers.
- Use a wide-tooth comb.
- If you are planning to have your child wear a wig, select it before all your child's hair comes out.

Side Effects of Chemotherapy (continued)

Side Effect	What You Can Do
SKIN AND HAIR PROBLEMS (continued)	
Hair loss (continued)	<ul style="list-style-type: none">• If you want to cover your child's head, try a variety of hats and scarves.• Protect your child's scalp from sun and cold.
Redness of skin	Call your doctor if redness, pain, or swelling occurs.
Dry, itching skin	Use mild soap and moisturizers. (If the child is receiving radiation therapy, check with your child's doctor before using moisturizer.)
Moist skin	Wash your child's skin 2–3 times each day. Pat dry with a clean towel and lightly powder with cornstarch.
Rashes	Call your child's doctor, who may order medication.
Sun sensitivity	<ul style="list-style-type: none">• Avoid sun exposure.• Use an SPF 30 or higher sun-blocking lotion.
Swelling, redness, or pain at the needle site where chemotherapy drugs are given	Certain drugs given intravenously can cause burns and sores on your child's skin if they leak out of the vein. Tell your doctor or nurse right away if leaking occurs.

Side Effects of Chemotherapy (continued)

Side Effect	What You Can Do
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KIDNEY AND BLADDER PROBLEMS

Bladder irritation and infection	<ul style="list-style-type: none">• Give your child plenty of fluids, especially on the day of treatment and on days before and after treatment. The amount of fluids depends on your child's size, so discuss this with your child's doctor.• Avoid giving drinks with caffeine.• Report to the doctor if your child has pain or burning when urinating, frequent urination, a feeling of having to urinate right away, reddish or bloody urine, or if he or she is not able to urinate.
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Change in urine color and strong urine odor	Some drugs cause the urine to turn orange, red, or bright yellow and to have a strong odor. Ask the doctor if a change in urine color is likely.
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NERVE PROBLEMS

Damage to nerves	Certain chemotherapy can damage nerves, causing difficulties with walking and talking or jaw pain. Call the doctor if any of these problems occurs.
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BONE PROBLEMS

Stress fractures	Some chemotherapy can weaken bones and cause stress fractures. Notify the doctor if your child develops pain in the arms or legs or if your child develops a limp.
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Side Effects of Chemotherapy (continued)

Side Effect	What You Can Do
SYSTEMIC PROBLEMS (involving the entire body)	
Fever	Call the doctor if your child's temperature goes over 100.4°F or 38°C. Do not give your child any over-the-counter medications to reduce the fever unless told to do so by the doctor.
Flu-like symptoms	Call the doctor. Symptoms may occur a few hours to a few days after chemotherapy. They include muscle aches, headache, tiredness, slight fever, chills, and poor appetite. These symptoms also may be from either an infection or the cancer.
Infection	<p>Many anticancer drugs lower the number of white blood cells, making it harder for the body to fight infection. Here is what you can do:</p> <ul style="list-style-type: none">• When possible, avoid taking your child into crowds. Also, avoid being around people with colds, flu, or any other contagious diseases, or anyone who has had a recent immunization with a vaccine containing live viruses (regular measles; German measles, or rubella; mumps; polio; and chickenpox).• Call the doctor if your child is exposed to known infectious illnesses (for example, measles or chickenpox).• If the white blood count falls too low, the doctor may postpone the next treatment or give a lower dose of drugs for a while.

Side Effects of Chemotherapy (continued)

Side Effect

What You Can Do

SYSTEMIC PROBLEMS (involving the entire body) (continued)

Anemia/fatigue

Chemotherapy can lower the bone marrow's ability to make red blood cells, causing anemia. Here is what you can do:

- Look for weakness, tiredness, dizziness, chills, or shortness of breath.
- Call the doctor if your child develops any of these symptoms.

Blood clotting problems (bleeding)

Chemotherapy can affect the body's ability to make platelets, the blood cells that help the blood to clot. Without enough platelets, your child may bleed or bruise more easily than usual; a blood transfusion may be needed. Here is what you can do:

- Look for bruises, small red or purple spots under the skin, bleeding from the gums or nose, reddish or pinkish urine, or black or bloody bowel movements.
- Call the doctor if your child develops any of these symptoms.

Swelling/fluid retention

- Call the doctor if you notice swelling or puffiness in your child's face, hands, feet, or abdomen.
- Your child's doctor may recommend limiting table salt and salty foods and/or order medicine to get rid of the extra fluid.

Allergic reaction

- Look for fever, fainting, rash, difficulty breathing.
- Call the doctor immediately. This side effect can be serious, but it is not common.

Long-term Side Effects of Chemotherapy

Ask your child's doctor and treatment team about health problems that may occur later as a result of the chemotherapy. A few chemotherapy drugs can cause lasting damage to the body's organs. For example, heart problems sometimes show up years after treatment, and children who have been treated with these drugs may need regular checkups by a cardiologist. Your child's later ability to have children may also be affected by chemotherapy. Finally, depending on the specific chemotherapy your child received, your child may be at risk of developing a second cancer.

Radiation Therapy

Radiation therapy is treatment with high-energy rays to damage or destroy cancer cells. Like surgery, radiation therapy is a local therapy. The rays are aimed at the part of the body that has cancer, and the treatment destroys cancer cells in the treated area. Doctors may use radiation therapy before surgery to shrink a tumor. After surgery, radiation therapy may be used to stop the growth of cancer cells that remain.

How Does Radiation Therapy Work?

All human body cells, including cancer cells, contain a substance called DNA. DNA tells the cells how to form and grow. In radiation therapy, the radiation harms the DNA inside the cancer cells, causing them to die before more cells are made. Tumors will shrink as the cancer cells die.

Getting Ready for Radiation Therapy

Before treatment begins, a doctor who specializes in radiation therapy will talk with you and your child about treatment. The doctor also will mark the exact area on your child where the radiation will be given. Marking ensures that the treatment is given in the same place each time. These marks, or small tattoos, are not painful to receive—the skin is only pricked—and they need to stay

in place all during treatment. Although the skin may become tender during radiation, it is important to avoid using any soaps or lotions near the markings or the part of the body receiving the radiation without the approval of the radiation team. Lotions are often okay if removed hours before treatment.

Because you would be exposed to radiation, you will not be allowed to stay in the room with your child during the treatment. Your child will not be radioactive during or after radiation therapy, so no one need fear being close to your child.

What Will Happen During Radiation Therapy?

Radiation therapy does not cause pain. It is much like having a regular x-ray taken, except that your child needs to hold still longer. Because some young children are often unable to be still, the doctor may give a young child medicine to help him or her relax or to put him or her to sleep. The parts of your child's body that are not being treated will be covered by special shields made of lead to protect those body parts from the radiation.

Lessening Your Child's Fears

Some children may find the machines scary. Most radiation departments will give you and your child a tour of the area before the first treatment, so both of you can see what the machines look like. Younger children may be afraid of being left alone in the room. You can tell your child that you will be right outside. In some hospitals, you may be able to see your child receive treatment through closed-circuit television or viewing windows; your child may feel better just knowing that you are watching.

Side Effects of Radiation Therapy

The high doses of radiation that kill cancer cells can also hurt normal cells. When this happens, side effects occur. With radiation therapy, the side effects depend on the treatment dose and the part of the body being treated.

The following chart gives information on the most common side effects of radiation therapy.

Side Effects of Radiation Therapy

Side Effect	What May Help
ALL RADIATION SITES	
Tiredness/ fatigue	Make sure your child gets extra sleep and rest.
Redness, blistering of skin	<ul style="list-style-type: none">• Leave the irritated skin open to the air.• Clean your child's skin as directed.• Use ointments only if the doctors approve.• Keep your child out of the sun as much as possible.• Use at least an SPF 30 sun-blocking lotion.
Hair loss (occurs only in the area being treated)	<ul style="list-style-type: none">• Your child's hair should grow back within weeks to 3 months after treatment ends, but some areas receiving higher doses may not grow back.• Use a mild shampoo.• Cut your child's hair short.• Avoid hair dryers and electric curlers.• Protect your child's scalp from cold and sun.• Use a wide-tooth comb.• If you plan to have your child wear a wig, select it before all your child's hair comes out.• If you want to cover your child's head, try different hats and scarves.• Ask your child's doctor for medicine

Side Effects of Radiation Therapy (continued)

Side Effect

What May Help

HEAD AND NECK RADIATION SITES

Sore mouth

(sprays, mouthwashes, and lozenges) for your child's mouth.

- Give your child a sponge toothbrush or cotton swab to brush his or her teeth.
- Have your child rinse his or her mouth every 2–3 hours and after meals using baking soda solution or water.
- Avoid mouthwashes that have a high alcohol content, which may irritate mouth sores.
- Avoid serving very cold, hot, spicy, or acidic foods.
- Try serving soft foods.
- Contact the doctor if your child has mouth sores, painful areas, or patches of red or white in the mouth.

Dry mouth

- Drink plenty of water.
- Suck on sugar-free hard candy or ice pops, or chew sugar-free gum.
- Rinse with a mouthwash recommended by the doctor.
- Serve foods with sauces, gravies, and salad dressings to make them moist and easier to swallow.
- Drink liquids with meals.

Side Effects of Radiation Therapy (continued)

Side Effect	What May Help
STOMACH AND ABDOMEN RADIATION SITES	
Nausea and vomiting	<ul style="list-style-type: none">• Ask your child's doctor about medicines to control nausea and vomiting and/or sedatives to help your child sleep through the nausea.• Feed your child light foods 3–4 hours before treatment.• Encourage your child to eat small amounts of food often and slowly.• Avoid serving sweet, greasy, and spicy foods and foods with strong odors.• Serve your child cold meals, such as sandwiches, instead of hot foods.• Encourage your child to take liquids first, and then wait 30–60 minutes before eating solids. Most children tolerate liquids better than solids.• Have your child rest after meals.• If your child is vomiting, do not give anything to eat or drink until it is under control. Once the vomiting is under control, give small amounts of clear liquids (for example, water, broth, milk-free ices, and gelatin desserts). Begin with 1 teaspoon every 10 minutes; gradually increase the amount to 1 tablespoon every 20 minutes; and finally, try 2 tablespoonfuls every 30 minutes. When your child can keep down clear liquids, try denser liquids (for example, strained cereal, pudding, yogurt, milkshakes, cream soups). Give small amounts as often as your child can keep them down. Gradually work up to solid foods.

Side Effects of Radiation Therapy (continued)

Side Effect

What May Help

STOMACH AND ABDOMEN RADIATION SITES (continued)

Diarrhea

- Contact your doctor if your child's diarrhea is severe, that is, more than three loose stools per day.
- Avoid giving your child apple juice.
- Avoid giving your child fatty foods.
- Try foods high in proteins and calories but low in fiber, such as plain or vanilla yogurt, rice with broth, or noodles.
- Serve your child foods and liquids high in sodium and potassium. Foods high in potassium that do not cause diarrhea are bananas, peach and apricot juices, and boiled or mashed potatoes.
- Make sure your child drinks plenty of liquids.

Long-term Side Effects of Radiation Therapy

Radiation therapy also may affect your child in the future. For example, radiation to the brain may cause learning and coordination problems, especially in very young children. Thus, it may be helpful to consider neuropsychological testing following treatment. Radiation therapy may also affect your child's growth or may cause a second cancer to form in the treated area years after treatment. Therefore, the doctor may delay radiation therapy or, if possible, choose another treatment, such as chemotherapy. Your child's treatment team has no way to know exactly what, if any, long-term effects your child may have, but they can help you know what the possible effects might be.

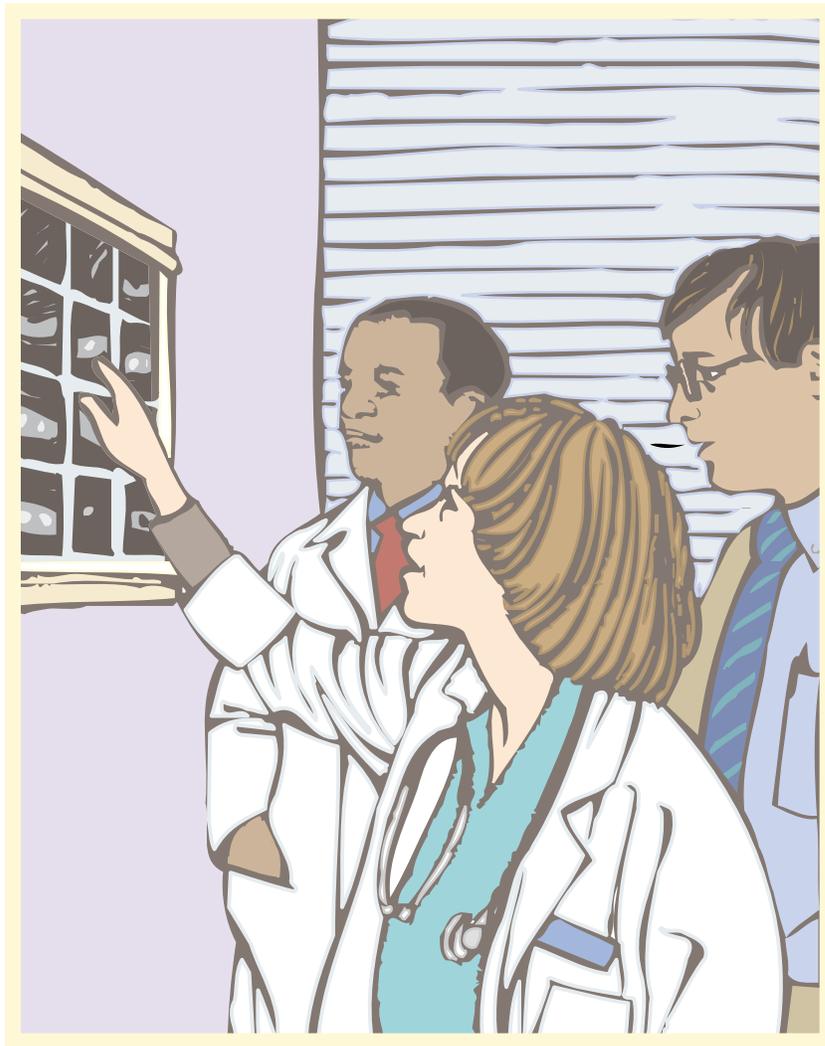
Immunotherapy

The immune system—the body’s system for defending itself—knows when substances that should not be there, such as bacteria and viruses, are in the body and then attacks them. The system also knows when cells have changed, such as when cells become cancerous, and then attacks them. **Immunotherapy**, also known as **biological therapy**, was developed to take advantage of the body’s own ability to fight disease.

In immunotherapy, substances called **biological response modifiers (BRMs)** are given to cancer patients. BRMs are substances that are normally made by the body to fight cancer and other diseases. Scientists can make large amounts of BRMs to use in cancer treatment. These BRMs destroy cancer cells and change the way the body reacts to a tumor. They may also help the body replace noncancerous cells destroyed by chemotherapy.

Several types of BRMs are used to treat cancer. Four are discussed here: **cytokines**, **interleukins**, **colony-stimulating factors**, and **monoclonal antibodies**.

- Cytokines are proteins formed in small amounts by all human cells to help control the working of cells. **Interferon**, one type of cytokine, helps the immune system slow the rate of growth and division of cancer cells, causing them to become sluggish and die. In children who have cancer, these agents have been tested against leukemia, osteosarcoma, brain tumors, and neuroblastoma.
- Interleukins, another type of cytokine, are made by lymphocytes. Interleukin-2, one of the most studied interleukins, causes certain kinds of white blood cells to grow and destroy tumors.
- Colony-stimulating factors are proteins that cause bone marrow cells to develop platelets, red blood cells, and white blood cells.



- Monoclonal antibodies recognize specific **antigens**, substances that the body senses do not belong or regards as “outsiders,” on the surface of cancer cells. These antibodies can be directed against a certain cell type. They can be used to attack and damage or destroy cancer cells. They may also be used to deliver anticancer drugs or radiation directly to specific cancer cells. This technique is still being developed and is used only in clinical trials.

Side Effects of Immunotherapy

Depending on the exact type of treatment, immunotherapy often causes flu-like symptoms such as chills, fever, muscle aches, weakness, loss of appetite, nausea, vomiting, diarrhea, and, at times, a rash. Sometimes the patient will bleed or bruise easily. Depending on how serious these problems are, hospitalization may be needed during treatment. These side effects usually go away after treatment ends. Ask your child's doctor about coping with the side effects.

Bone Marrow and Peripheral Blood Stem Cell Transplants

Some children who have leukemia or other types of cancer may need a bone marrow transplant (BMT) or a peripheral blood stem cell transplant (PBSCT). In these treatments, the blood cells in the diseased or damaged bone marrow—the spongy material that fills the inside of bones and makes blood cells—are replaced with healthy cells (stem cells), which will grow new healthy cells.

Stem cells are immature cells that produce the three types of blood cells:

- white blood cells, which fight infection
- red blood cells, which carry oxygen to and remove waste products from organs and tissues
- platelets, which enable the blood to clot.

Most stem cells are found in the bone marrow, but some—called peripheral blood stem cells (PBSCs)—are collected from the bloodstream. Umbilical cord blood also contains stem cells. If your doctor proposes a stem cell transplant for your child, the stem cells may come from a donor's bone marrow, bloodstream, or umbilical cord blood or from your child's own bone marrow or bloodstream.

Healthy stem cells grow in two ways:

- They divide to form more stem cells.
- They mature into white cells, red cells, and platelets.

When transplanted into a cancer patient, stem cells can rescue the damaged blood-forming system.

Two circumstances create the need for a transplant. The first is when the cancer itself has injured the bone marrow. BMT and PBSCT are commonly used in the treatment of leukemia and lymphoma. The second circumstance is when a treatment requires such large doses of chemotherapy or radiation therapy that the child's bone marrow is damaged during treatment. Chemotherapy and radiation therapy target all cells that divide rapidly. Cancer cells divide more rapidly than most healthy cells and so are destroyed by the therapies. Bone marrow cells, however, also divide more rapidly than other healthy cells, so high-dosage treatment can have a damaging effect on them as well.

A BMT or PBSCT can be done in three ways: as an autologous transplant, an allogeneic transplant, or a syngeneic transplant.

- **Autologous transplant**—The child's own stem cells or PBSCs cells are used. They can be obtained from the bone marrow or from blood, using the apheresis procedure. Stem cells are collected while the child is in **remission** (when the signs and symptoms of cancer have disappeared). To make sure that any cancer cells that remain are destroyed, the marrow may be treated with anticancer drugs. After the marrow or PBSCs are collected, the child receives high-dose chemotherapy, usually over 2 to 6 days, and, frequently, total body irradiation, during which the whole body is radiated, in one dose or in many doses over several days, to get rid of the cancer. The collected marrow or PBSCs are then returned to the child through a vein, as in a blood transfusion.
- **Allogeneic transplant**—The marrow or PBSCs from a sibling, parent, or someone not related to the child are used for the transplant. The transplant material must be as closely matched to the patient's blood cells as possible. Cord blood transplant is allogeneic.
- **Syngeneic transplant**—The perfectly matched marrow or PBSCs from an identical twin are used for the transplant.

Before the transplant, a catheter is usually inserted into a large vein in the chest for transplanting the marrow or PBSCs, as well as for giving blood, antibiotics, and other drugs and for drawing blood. The child is given high doses of anticancer drugs and/or radiation. When the cancer cells—along with some healthy bone marrow cells—are destroyed, the new, healthy marrow or PBSCs can be given. The healthy marrow or PBSCs are given through the catheter and travel through the bloodstream to the bone marrow where they start to make red and white blood cells and platelets.

It usually takes 14 to 30 days after the transplant for the transplanted stem cells to make enough white blood cells to fight infection and to make other blood cells. During this time, your child will be at higher risk for infections, anemia, and bleeding. Complete recovery of your child's immune system can take 1 to 2 years after an autologous, allogeneic, or syngeneic transplant. Your child may need to remain in a hospital room that is kept as free as possible from anything that may cause an infection. Supportive care, which includes receiving blood transfusions and antibiotics, will be given.

Supportive Care

Children having a BMT or PBSCT usually stay in the hospital for 1 to 2 months (sometimes longer), although outpatient BMT can be done for children who have brain tumors. Children receiving BMT or PBSCT may need **supportive care**.

For more information on side effects from chemotherapy and radiation therapy, see the charts in those sections.

Graft-Versus-Host Disease

Graft-versus-host disease (GVHD) may occur in patients who receive bone marrow or peripheral stem cells from a donor. In GVHD, donated stem cells realize they are in a different body, so they may attack the patient's tissues, such as the liver, skin, or digestive tract. GVHD can be mild or very severe and can occur any time after the transplant—even years later. The doctor may give drugs to reduce the risk of GVHD and to treat the problem if it occurs.

Supportive Care for BMT and PBSCT

Problem	Supportive Care Provided
Low counts of all types of blood cells	<ul style="list-style-type: none">• Isolation from people with infectious diseases• Transfusion with blood products, including platelets and red blood cells• Treatment with proteins that increase the number of white blood cells
Infections	<ul style="list-style-type: none">• Intravenous antibiotics• Isolation from other people
Gastrointestinal infections	<ul style="list-style-type: none">• Low-bacteria diet• Mouth care• Liquid antibiotics
Difficulty eating enough food	Intravenous nutrition—giving nutrients through a vein

What about Complementary and Alternative Medicine?

Complementary and alternative medicine (CAM) includes a broad range of healing philosophies, approaches, and therapies. A therapy is generally called complementary when it is used in addition to conventional treatments; it is often called alternative when it is used instead of conventional treatment. (Conventional treatments are those that are widely accepted and practiced by the mainstream medical community.)

It is important that the same scientific evaluation used to assess conventional treatments be used to evaluate complementary and alternative therapies. Conventional cancer treatments have generally been studied for safety and effectiveness through clinical trials, which are research studies with people. Some complementary and alternative therapies have not been studied in clinical trials.

Questions to Ask Your Child's Health Care Provider About Complementary and Alternative Therapies—

- What benefits can be expected from this therapy?
- What are the risks associated with this therapy?
- Do the known benefits outweigh the risks?
- What side effects can be expected?
- Will the therapy interfere with conventional treatment?
- Is this therapy part of a clinical trial? If so, who is sponsoring the trial?
- Will the therapy be covered by health insurance?

Others, which once were not accepted by the mainstream medical community, are gaining acceptance in cancer therapy—not as cures, but as complementary therapies that may help patients feel better and recover faster. One example is acupuncture. Other therapies, such as laetrile, have been studied and found to be ineffective and potentially harmful.

If you have questions about complementary or alternative therapies, discuss them with your child's doctor or treatment team.

What about Hospitalization?

Being in the hospital is often scary for any child, especially at first. It is a whole new world to learn about—new people and strange machines, procedures, and routines. Adding a touch of home by having pictures of family members and friends, drawings, and other personal things in your child's room can help make the hospital a less scary place. These homey touches can help start a conversation between the hospital staff and your child.

One of the scariest things for many children is being separated from their parents and siblings. Many hospitals and treatment centers help your family and your child spend as much time together as possible by allowing you to visit anytime and having beds for parents in the child's room or bedrooms nearby. If the hospital does not have beds for you, you might ask to sleep in a chair near your child's bed.

Most hospitals have playrooms for children who are patients. Playrooms often have toys, games, arts and crafts supplies, and tape players, giving children a chance to play and talk with each other in much the same way that they do with their friends at home or in school. The playroom setting allows children to relax and become more comfortable in the hospital. Playroom staff, trained in working with children who have serious illnesses, can talk to parents and other members of the treatment team about the fears or concerns a child may share through play.

If your child cannot get out of bed to go to the playroom, child-life workers—trained staff who help coordinate play, school-work, and other activities for the child—may make bedside visits.

For older children who are trying to separate themselves from you and be more on their own, being in the hospital may thwart their drive for independence. At a time when young people are normally doing more on their own, cancer makes them rely on you more. As a result, adolescents may make it known, loudly and often, that they are unhappy. They may refuse treatment, break hospital rules, miss outpatient appointments, and rebel in other ways.



Children of any age will often cooperate more if given treatment choices that do not cause problems with their care. Parents can help children become more independent by allowing them to share the responsibility for their care. Some hospitals also make a special effort to help children cope with illness and being in the hospital, such as allowing teenagers to dress in street clothes whenever possible and to have friends visit. Some hospitals have equipment that allows the child to interact with his or her classmates in their classroom.

What Are the Common Medical Procedures?

Medical tests and procedures are not only used to diagnose cancer, but also to see how well the treatment is working and to make sure that the treatment is causing as little damage to normal cells as possible. Many of these tests will be repeated from time to time throughout treatment.

Parents and children say that knowing about the tests before they are done helps them to cope. You may want to ask your doctor these questions before any testing is done:

- Which tests will my child have? What will my child need to have this test? An IV? An oral contrast?
- Where and how is each test done?
- Will the tests be painful? If so, what can be done to make my child more relaxed and in less pain?
- Who will do the tests? Has the staff doing the testing worked with children?
- What information does the doctor expect to get from the tests?
- How soon will the results be known? What do the results mean?
- Will the tests be covered by insurance?

Some of these tests are painful; most are not. For some tests, your child may need to remain still for as long as an hour. Ask your doctor what you and the treatment team can do to help your child become more comfortable during the tests. For procedures that require your child to remain very still, medicines can be given to help your child relax or become sleepy. For tests that can be

painful, such as the **bone marrow aspiration** test and **spinal tap**, pain medicines are often given. Sometimes a general anesthetic, a drug that causes your child to lose consciousness and all feeling, is given.

Relaxation therapy (methods used to make one feel more relaxed and to feel less pain), **guided imagery** (using the imagination to create mental pictures), **hypnosis** (a trance-like state that can be brought on by a person trained in a special technique), music, and other techniques can also help to ease your child's discomfort and fear. When your child is relaxed, the procedures are less painful. Ask your treatment team to help you guide your child through relaxation exercises both before and during the procedures. Often a combination of pain medicine and relaxation techniques is used.

Your child will want to be with you during the procedures, and in most situations, that is possible. See the chapter "What Are Some Common Health Issues?" (page 63) for detailed information on pain control and relaxation. The following chart provides information about some common medical procedures your child may have.

Common Medical Procedures and Tests

Procedure/Test	Purpose	What is Done
BIOPSY		
General	A biopsy determines if a tumor is not cancerous (benign) or cancerous (malignant). If the biopsy is "positive," cancer is present. If it is "negative," cancer cells were not seen.	A doctor removes part or all of the tumor or part of the bone marrow. A pathologist, a doctor who specializes in recognizing changes caused by disease in humans, looks at the tissue under a microscope.
Bone marrow aspiration or bone marrow biopsy	This type of biopsy examines the bone marrow under a microscope to see if leukemia is present or if the treatment is working. For other cancers, this test tells whether the disease has spread to the bone marrow.	For young people, a bone marrow test is most often done in the hip bone. The child lies on his or her stomach with a pillow under the hips. A needle is put through the skin and into the middle of the hipbone, and a small sample of marrow is quickly drawn into the syringe. The most painful part of the test lasts for a few seconds.
BLOOD STUDIES		
Tumor markers	This type of test searches for substances that may increase in the blood of a person with cancer. It can help to diagnose cancer and to find out how well the child is responding to treatment.	A sample of blood is usually obtained through a needle inserted in a vein or by pricking the tip of the finger and squeezing out a few drops of blood. Sometimes blood is obtained via tubes

Common Medical Procedures and Tests (continued)

Procedure/Test	Purpose	What is Done
BLOOD STUDIES (continued)		
Tumor markers (continued)		(catheters) that have been surgically placed through the chest and into one of the major blood vessels leading to the heart.
Complete blood count (CBC)	A CBC test checks the white blood cells, hemoglobin, hematocrit, and platelet count in a sample of blood.	See above.
White blood cell (WBC) count	A WBC count measures the number of WBCs in the blood and is also used to find certain types of immature cells—called blast cells—typical of leukemia. WBCs protect the body from infection. Chemotherapy and other treatments can lower the number of WBCs, increasing the risk of infection. If the test reveals a low WBC count, treatment may need to be delayed until the count goes up.	See above.
Hemoglobin	Hemoglobin is the substance in red blood cells that carries oxygen to the body's tissues. Low	See above.

Common Medical Procedures and Tests (continued)

Procedure/Test	Purpose	What is Done
BLOOD STUDIES (continued)		
Hemoglobin (continued)	hemoglobin indicates anemia. Anemia can cause your child to look pale and feel weak and tired. It may be a side effect of chemotherapy or a sign that the cancer has returned.	
Hematocrit	Hematocrit determines the size, function, and number of red blood cells. A low hematocrit also may mean that anemia is present.	See above.
Neutrophils (also called ANC-absolute neutrophil count)	This blood study tests for the body's ability to fight bacterial infections.	See above.
Platelet count	This test measures the number of platelets. Platelets help the blood clot. A low platelet count, which may be due to side effects of medicine or to infection, or may mean that leukemia is present, could cause one to bleed or bruise easily.	See above.

Common Medical Procedures and Tests (continued)

Procedure/Test	Purpose	What is Done
LUMBAR PUNCTURE		
Lumbar puncture or spinal tap	This test obtains a sample of spinal fluid—the liquid that surrounds the brain and spinal cord. The doctor looks at the fluid under the microscope to see if any infection or cancer cells are present. It is also used to give anticancer drugs directly to the brain and spinal cord.	The child, in a curled position, lies on one side or sits. A needle is inserted between the small bones of the spine into the fluid space around the spinal cord. A sample of the spinal fluid is taken. This test can be somewhat painful.
IMAGING TESTS		
General	Imaging tests take pictures or images of areas inside the body to see what is happening.	Tests are generally not painful, but the equipment may be frightening to children. Some machines, such as MRIs, make very loud noises.
Angiogram	An angiogram obtains an x-ray of the blood vessels and shows changes in the blood vessels and in nearby organs. Clogged blood vessels or blood vessels that have moved may mean that a tumor is present.	A special dye is injected into an artery and travels through the blood vessels. Then a series of x-rays is taken. The dye makes the blood vessels show up on an x-ray.

Common Medical Procedures and Tests (continued)

Procedure/Test	Purpose	What is Done
IMAGING TESTS (continued)		
Ultrasound	Ultrasound obtains a picture of part of the body by using sound waves. The waves echo or bounce off tissues and organs, making pictures called sonograms. Tumors have different echoes than normal tissues, making it possible to “see” abnormal growths.	A small hand-held device called a transducer is used to send the sound waves to a site in the body. The transducer is rubbed firmly back and forth over the site after the skin has been lubricated with a special gel.
Radioisotope scanning	This test studies the liver, brain, bones, kidneys, and other organs of the body.	The child either swallows or has an injection of a mild, radioactive material that is not harmful. After a short wait, a scanning device is passed over the body to detect where the radioactive material collects in the body and allows the doctor to locate tumors. Your child will not be radioactive during or after these tests.

Common Medical Procedures and Tests (continued)

Procedure/Test	Purpose	What is Done
IMAGING TESTS (continued)		
<p>CT scan (computerized tomography scan) or CAT scan</p>	<p>This test obtains a three-dimensional picture of organs and tissues; ordinary x-rays give a two-dimensional view. Using pencil-like x-ray beams to scan parts of the body, a CT also gives better pictures of soft tissues than does an x-ray. It provides precise and very useful details about the location, size, and type of tumor.</p>	<p>While the child lies still, a large machine moves back and forth, taking pictures.</p> <p>The scan takes 30–90 minutes. Sometimes a special dye is injected into a vein before the scan.</p> <p>If your child has a central venous line in the chest, it generally cannot be used during a CT scan of the chest. It is important to prepare your child for an IV in the hand.</p>
<p>MRI (magnetic resonance imaging)</p>	<p>An MRI creates pictures of areas inside the body that cannot be seen using other imaging methods. MRI uses a strong magnet linked to a computer. Because an MRI can see through the bone, it can provide clearer pictures of tumors located near the bone.</p>	<p>The child lies on a flat surface, which is pushed into a long, round chamber. Your child will hear a loud thumping noise, followed by other rhythmic beats. The test takes 15–90 minutes, during which your child must lie still.</p> <p>Sometimes a special dye is injected into a vein before the test.</p>

What Are Some Common Health Issues?

Pain relief, nutrition, treatment for infections, immunizations, bleeding, transfusions, and dental/mouth care are all part of supportive care. The goal of supportive care is to prevent or lessen the side effects of the treatment and the disease. With this care, your child can receive the needed therapy with greater safety and comfort. You may want to talk with your child's doctor or other members of the treatment team to see how the information provided below might help your child.

Pain

Your child may have pain for a variety of reasons. Pain may be caused by the cancer itself, or it could be from the treatment, such as surgery to remove a tumor or side effects of chemotherapy. Sometimes, cancer patients have pain that has nothing to do with the cancer, such as a toothache or a headache.

- Not all children with cancer have pain. Those who do are not in pain all of the time.
- Medicine and other treatments can almost always relieve cancer pain.
- Relieving pain will not only make your child more comfortable, but also may help your child sleep and eat better.
- Parents often feel helpless when their children are in pain. This reaction is natural. Knowing what to expect and what can be done to relieve pain can help. Talk with the doctor and treatment team about whether your child is likely to have pain, what pain treatment your child can receive, or what to do for your child if pain occurs.

How Is Pain Managed?

The best way to relieve pain is to treat its cause. If a tumor is causing pain, the doctor may try to remove the tumor or decrease its size using surgery, radiation therapy, and/or chemotherapy. Other ways to relieve or control pain include use of:

- direct pressure or cold or warm compresses
- pain medications
- **physical therapy** (the health profession that treats pain in muscles, nerves, joints, and bones with exercise, electrical stimulation, hydrotherapy, and the use of massage, heat, cold, and electrical devices)
- relaxation
- **distraction** (turning your child's attention to something other than the pain)
- imagery (using your child's imagination to create mental pictures or situations). Most cancer centers have a psychosocial team that can help you learn, or help your child learn, the techniques of relaxation, distraction, and imagery
- **nerve blocks** (a method in which medicine is injected into or around the nerve to numb or deaden the nerve fibers).

Preventing pain from starting or getting worse is the best way to control it. Some people call this “staying on top of the pain.” It may also mean that your child will need a lower dose of a pain reliever than if you wait until the pain gets bad. Different pain medicines take different lengths of time to work, from a few minutes to several hours. If your child waits too long to take pain medicine, the pain may get worse before the medicine helps.

To treat your child's pain, the doctor may start with medicines such as acetaminophen. If the pain increases, stronger drugs that require a prescription may be needed. Sometimes, opioids (also known as narcotics) are prescribed. Narcotics are the strongest pain relievers available. Studies show that taking narcotics to

relieve cancer pain will not make your child addicted to drugs. When your child is taking opioids, talk to the doctor, nurse, or pharmacist before giving him or her any other medications.

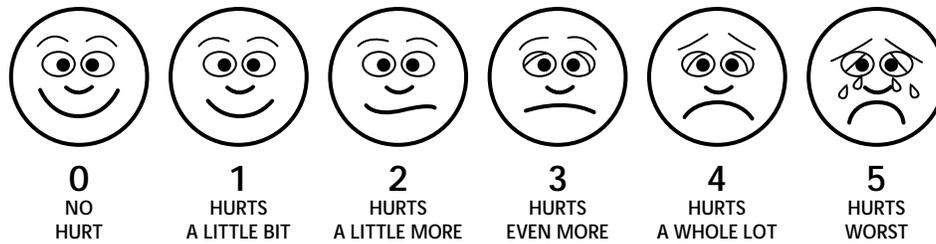
Work closely with the treatment team in sharing information about your child. For example, if you know that your child is afraid of needles, ask the doctor if your child can be given oral medicine. In older children and adolescents, the doctor may order a self-controlled drug “pump.” This method uses a portable computerized pump containing pain medicine attached to a needle that is placed in a vein or attached to the central vein catheter. When pain relief is needed, the child presses a hand-held button, and the pump injects a preset dose of medicine into the vein. Pumps are programmed to give preset doses only at preset intervals, so even if the child presses button more than once during the preset interval, he or she will not get any more pain medication than is programmed.

How Will I Know How Bad My Child’s Pain Is?

Treating pain in children requires a special understanding of the child and of the child’s age. In some cases, you may need to speak for your child, especially if your child is younger than 4 years old. For infants and very young children, you can be of great help by closely watching the expressions on your child’s face and carefully listening to the way your child cries. Take note of changes in behavior, such as sadness or isolation or decreased activity. The changes may mean that your child is in pain.

Sometimes, children have pain, but they may not be able to tell you about it. They may be afraid to. It is important to ask if your child has pain. Talk with your child about where and how much pain there is. Use words that your child knows, such as “boo-boo” or “ouch.” A good way to determine the amount of pain your child has is to use a pain scale. A frequently used pain scale is the Wong-Baker FACES Pain Rating Scale, which can be used with children as young as 3 years old. On this scale, each face demonstrates a level of pain, from a person who feels happy because there is no pain (hurt) or sad because there is some or a lot of pain. Face 0 is very happy because there is no hurt. Face 1 hurts just a little bit. Face 2

hurts a little more. Face 3 hurts even more. Face 4 hurts a whole lot, but Face 5 hurts as much as you can imagine, although you do not have to be crying to feel this bad. Ask your child to choose the face that best describes the pain. Report the number under the chosen face to your child's nurse and doctor.



From Wong, D.L., Hockenberry-Eaton, M., Wilson, D., Winkelstein, M.L., Ahmann, E., DiVito-Thomas, P.A.: Whaley and Wong's Nursing Care of Infants and Children, ed. 6, St. Louis, 1999, p. 2040. Copyrighted by Mosby, Inc. Reprinted by permission.

What If the Pain Is Not Being Controlled?

Cancer pain almost always can be greatly lessened or relieved, but no doctor can know everything about all medical problems. If your child's doctor is unable to control your child's pain, ask to see a pain specialist. Pain specialists may be oncologists, anesthesiologists, neurosurgeons, other doctors, nurses, or pharmacists. A pain control team may also include psychologists and social workers.

For more information about pain control, you and your child's treatment team may find these NCI booklets helpful:

- Pain Control: A Guide for People With Cancer and Their Families (available from both NCI's Cancer Information Service [CIS] and the American Cancer Society)
- Get Relief From Cancer Pain
- Understanding Cancer Pain

You can receive copies from the CIS by calling 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615. Also, many NCI publications may be viewed or ordered on the Internet at <http://cancer.gov/publications>.

Diet

Many side effects from cancer treatment may make it hard for your child to eat. Some physical side effects include loss of appetite, sore mouth, changed sense of taste, nausea, vomiting, diarrhea, constipation, and weight gain. The emotional side of cancer treatment may also affect your child's eating habits. When children are upset, worried, or afraid, they may have eating problems. Losing his or her appetite and feeling nauseated can be normal when your child is nervous or afraid. The treatment team, including the nutritionist/dietitian at the hospital where your child receives treatment, can help you plan the food to serve at home. Let the team know if you notice that your child is losing or gaining weight. Ask what has worked for other children. The good news is that even children who have trouble eating have days when eating is a pleasure. The following suggestions may help your child feel more like eating:

Serve appealing food.

- Build meals around your child's favorite foods, but do not force favorite foods during nausea attacks. Forcing may cause a lasting dislike of the food.
- Try always to give high-calorie foods (for example, macaroni and cheese with real butter and cheese, or milkshakes made with ice cream). Add instant breakfast powders to all milk and milk products.

Adopt a casual attitude about mealtimes.

- Let your child eat whenever he or she is hungry or offer food often during the day. Have high-calorie, high-protein snacks handy. Taking just a few bites of the right foods or sips of the right liquids every hour or so can help increase your child's intake of proteins and calories. You can freeze portions of a favorite dish and serve them when your child wants them.
- Oral medicines may affect your child's appetite. Some are best given in the morning, some at midday, and some on a

full stomach. Ask the doctor when and how medicines should be given. Tell the doctor if your child has no appetite or has any other side effects.

- Try changing the time, place, and surroundings of meals. A picnic, even if it is in the house, can make mealtime more fun. Watching a favorite TV show or inviting a special friend to join your child at meal- or snacktime also can help your child feel more like eating.

Create a pleasant setting.

- Make mealtimes calm and relaxed. Do not hurry meals.
- Praise good eating. Try using small rewards, such as a favorite dessert or a new toy, to encourage good eating. Siblings should be considered when setting up a reward system. It is important that siblings are not left out, but be careful not to encourage healthy siblings to overeat.
- Avoid arguing, nagging, or punishing. Forcing a child to eat may make things worse.

If your child's eating becomes a serious problem, ask your child's doctor about medicines that can improve appetite.

Sometimes children gain extra weight during treatment because of the buildup of excess water in the body. Do not put your child on a diet. Instead, call the doctor. If the weight gain is due to extra water, the doctor may recommend using less salt, because salt causes the body to hold onto water. The doctor may also order medicines called diuretics to get rid of the excess water.

Children who have cancer need diets high in both calories and protein. High-calorie foods help prevent weight loss, and protein foods help the body stay strong and repair itself. To get your child to eat more protein and calories, try these tips.

- Offer liquids during the day, but not at mealtimes. Liquids are filling and take away an appetite for solid foods. Give your child a straw to make drinking easier.

- Some types of chemotherapy may change your child's sense of taste for a while. Well-seasoned foods, such as spaghetti, tacos, and pizza, may seem good at such times. Sometimes, adding extra salt or sugar, or using less, may make foods taste better.
- Avoid empty-calorie foods, such as soft drinks, chips, and candy, that can make your child's appetite worse without providing good nutrition. Milkshakes, yogurt, fruit, juices, or "instant breakfasts" provide extra calories and protein.

You will also find many helpful suggestions in NCI's booklet *Eating Hints for Cancer Patients*, available from the CIS at 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615. It is also available on the NCI Web site at <http://cancer.gov/publications>.

Infections

Infections are common in children who have cancer, especially in children who are receiving chemotherapy. Chemotherapy lowers the white blood cell count, which increases the chances of infection. You should report any sign of infection, such as a fever, to your child's doctor right away.

Infections are usually caused by bacteria or viruses. To find the cause of your child's infection, the doctor may take samples (**cultures**) of the throat, blood, urine, or stool. If the infection is from bacteria, your child will receive antibiotics. Antibiotics will not work against viruses. Unless a virus has been identified, however, most children are treated with antibiotics until their blood counts improve, even if bacterial infection cultures are negative. Your child may receive other medicines to help ease the symptoms. If the infection is serious, or the white blood cell count is very low, your child may need to be treated at the hospital. Your child's doctor may also stop the cancer treatment for a short time until the infection is gone.

Some viral infections, such as chickenpox, can cause major problems for a child receiving chemotherapy. Call the doctor right away if your child is exposed to chickenpox or to anyone who has recently received the chickenpox vaccine. And ask your child's



teachers to let you know if a schoolmate develops chickenpox. Some families ask teachers to ask schoolmates' families to call them at once if chickenpox develops in their families.

Once children have had chickenpox, they usually do not get it again, but some children on chemotherapy who have already had chickenpox may develop shingles. Shingles is a blister-like skin rash that looks like chickenpox. Instead of appearing all over the body, however, shingles is in just one area. Call the doctor right away if you think that your child may have shingles.

Regular or red measles (also known as rubeola or 9-day measles) may also be more serious for a child on chemotherapy. If your child comes into contact with this type of measles, you should call the doctor. The doctor may give your child medicine to prevent or control the infection.

Immunizations

Most vaccines, and especially live virus vaccines (regular measles, German measles or rubella, mumps, polio, and chickenpox), should not be given to a child receiving cancer treatment, although some doctors do recommend varicella (chickenpox) vaccines for children with cancer and for their siblings. Some immunizations may be dangerous because chemotherapy cancer treatment lowers the body's ability to protect itself when given these vaccines. In addition, brothers or sisters should not receive the live polio vaccines while their sibling is having cancer treatment. You should discuss these matters in detail with both your child's oncologist and your children's primary care provider (for example, pediatrician, clinic, or family physician).

Vaccines that are not live may be safe to give during cancer treatment, including diphtheria, whooping cough, and tetanus immunizations (DPT, DT, or IPV shots). Flu shots are okay, but you should ask your child's doctor before any immunizations are given.

Bleeding

Platelets are blood cells that help the blood to clot. A low platelet count may cause your child to bleed more easily than usual. If your child's platelet count is low, he or she will need to avoid contact activities such as football, soccer, or skateboarding. If bleeding occurs, you may try the following:

- Apply pressure until the bleeding stops—a clean towel, handkerchief, or cloth firmly pressed to the wound will slow or stop the bleeding.

- For nosebleeds, have your child sit up; do not let your child lie down. Pinch the bridge of the nose over the bone for 5 minutes. The pressure must be tight on both sides to stop the bleeding.

If bleeding continues, call the doctor immediately.

Transfusions

Children who have cancer may need to receive whole blood or blood components (such as red blood cells). This procedure is called a transfusion. Packed red cells are often given to control anemia—a condition in which the blood becomes low in red blood cells or in hemoglobin. A platelet transfusion is given if the platelet count is low. White cell transfusions are not routinely given when white blood cell count is low. The doctor may, however, consider white cell transfusions when a child with a very low white cell count has a very serious infection that is not responding to antibiotics.

Each person has a certain type of blood. Each person can only receive the blood of the same type or from the universal donor type “O.”

Dental/Mouth Care

If possible, your child should have a complete oral exam and any needed dental work before cancer treatment begins. Dental care is important during treatment, but even checkups should be avoided when blood counts are low. Always check with the doctor before starting any dental work, and let the dentist know your child is receiving cancer treatment. Your child may need to take an antibiotic before any dental work is done to prevent possible infections. In general, a low dose of amoxicillin is given before even a routine cleaning to patients who have a central venous catheter.

Keeping the child’s teeth, mouth, and gums clean to protect against decay is especially important. Make sure your child’s teeth are brushed after each meal, using a soft toothbrush. After each use,

rinse the brush well with cold water, shake it well, and allow it to dry. Give your child paper cups to rinse his or her mouth. Dental floss may be used if care is taken not to cut or irritate the gums.

Mouth Care During Radiation Therapy

During radiation to the head and neck, less saliva is produced, so the mouth becomes dry. This dryness can lead to tooth decay. The doctor or dentist may recommend using a fluoride mouth rinse or order a fluoride gel. Check with your doctor before buying a mouthwash—many can cause burning pain in a child with a sore mouth. All children receiving radiation should rinse their mouths often during the day. One suggested mouth rinse is a mixture of salt and baking soda (1/2 teaspoon of each in a cup of water). To care for infants and toddlers, wrap a soft cloth around your finger and gently wipe the teeth and gums with the mouth rinse. Soft “toothettes” can also be used to apply the rinse to the child’s mouth.

Mouth Care When Blood Counts Are Low

When your child’s blood counts are low, mouth care needs to be especially gentle; your child can get an infection or start bleeding more easily. Use very soft bristle toothbrushes, cotton or glycerin swabs, or toothettes, and avoid using water jet devices or dental floss. Call the doctor if you see any red or white patches, mouth sores, or irritated areas in the mouth.

Mouth Care When Your Child Has Mouth Sores

When mouth sores, bleeding areas, or irritated areas occur, use only the mouth rinse described above or one the doctor recommends. Your child should rinse the mouth out well after every meal and before bedtime. Cotton or glycerin swabs or toothettes (available in drug stores) can help remove pieces of food from the mouth. If mouth sores become painful, a local anesthetic may help. The doctor can order an anesthetic and will tell you how often to use it. To make eating easier, put the anesthetic on the sore gums before meals. For dry lips, try a lanolin lip ointment to prevent them from cracking and becoming sore.

When Should You Call the Doctor?

If you have worried about knowing when to call the doctor, you are not alone. Parents want to watch closely for any sign that their child may need to see the doctor but may not be sure what those signs are. They also may worry about “bothering” the doctor or treatment team. The best approach is to ask the doctor when to call about any problems your child may be having. If you are unsure, this list can be used as a guide for when to call the doctor.

Call the Doctor If...

Your child shows signs of infection.

- Fever (100.4°F or 38°C) or other sign of infection, especially if your child’s white count is low. (The doctor will tell you when it is low.) It is important to take your child’s temperature with an accurate thermometer.

Your child has trouble eating.

- Mouth sores that keep your child from eating
- Difficulty chewing

Your child has digestive tract problems.

- Vomiting, unless you have been told that your child may vomit after the cancer treatment
- Painful urination or bowel movements
- Constipation that lasts more than 2 days
- Diarrhea

Your child shows changes in mobility or mood.

- Trouble walking or bending
- Trouble talking
- Dizziness
- Blurred or double vision
- Depression or a sudden change in behavior

Your child has troublesome symptoms.

- Bleeding, including nosebleeds, red or black bowel movements, pink, red, or brown urine, or many bruises
- Severe or continuing headaches
- Pain anywhere in the body
- Red or swollen areas

Your child needs treatment for other health concerns.

- Before your child receives immunizations or dental care, even scheduled vaccinations or regular dental checkups
- Before you give your child any over-the-counter medication

You are in any doubt whatsoever!

You can find more information about these topics in this booklet under “What Are Some Common Health Issues?” (page 63).



How Do You Move on with Life?

One of the challenges facing the family of a child who has cancer is going on with everyday life. Moving forward is not an easy task. It may be hardest during times of stress: when you find out your child has cancer, when your child is in the hospital, or when your child is suffering from the side effects of treatment.

Even when the treatments are going well, the cancer still affects each member of your family. When your child enters the hospital or goes for treatments, each member has to adjust in some way. Family members may be apart. Days of work may be missed. Brothers and sisters may feel left out. Everyone may be worried and tense.

Despite all this, family life goes on. Brothers and sisters have school and activities. Parents have jobs. It is hard to keep up with everyday activities and responsibilities while being with and caring for your child with cancer.

As the mother or father of a child who has cancer, remember that you are not alone. You can get help from many sources, such as the treatment team, which includes a social worker who can help you in dealing with your child's illness; other parents of children with cancer; support groups; or others. (You can find more information about resources on page 92.) The information below may also be helpful for you, your child, the other children in your family, your extended family, and friends.

Life Goes On

Your Child

Even with a diagnosis of cancer, your child still has the same needs as other young people—going to school, having friends, and enjoying things that were a part of life before cancer. You can help meet these needs by letting your child live as normal a life as possible. Some activities, however, may need to be changed at different times during treatment. After chemotherapy or radiation therapy, your child may be very tired and, therefore, need more rest. This tiredness is to be expected. Help your child find other things to do, such as new hobbies, or ask friends to come over to draw or paint.

School and Friends

Encourage your child to stay in touch with friends. Keeping contact is easier if your child can continue to go to school while being diagnosed and treated, but staying in school is not always possible. If time off from school is needed, it is best for your child to return to school as soon as possible. Children who have cancer need and like to be with others their age, and keeping up with schoolwork makes them feel good about themselves. Some cancer centers offer back-to-school programs, which may help children and classmates understand the diagnosis and know what to expect. You may ask your doctor, nurse, or child-life specialist to visit your child's classroom.

Children often worry about how their friends and classmates will act toward them, especially if they have missed a lot of school or return with obvious physical changes, such as hair loss or a missing limb. Other students are usually accepting, but they may have questions. Help your child to think of ways to answer their questions and to tell friends and classmates that they cannot “catch” the disease. Your treatment team has had experience helping families with school. Ask them to help your child. Ask your nurse if the team or hospital has a school reentry program. Such programs send nurses to the child's classroom to talk about the child's cancer and treatment with classmates and teachers.

Your child needs to know that many people, including children,

To help your child and his or her siblings deal with fears and feelings, you may want to:

- Say “I love you” often.
- Assure your children that the cancer and its treatment are not punishments.
- Encourage your child or children to talk about the cancer and cancer treatment. Ask your children questions to get the conversation started. Family talks can help everyone feel less worried. Talking helps the whole family cope with the illness together.
- Tell your children that it is okay to feel sad and cry.
- Encourage activities to help your child feel more relaxed. Drawing, playing with harmless medical supplies or puppets, and role-playing may help your child feel better.

In addition, setting limits for behavior and activities is still important and even comforting to your child. But it is helpful to remember that children, like adults, have good days and bad days. Help your child feel part of normal life.

- Allow your child to make choices as long as they do not cause problems with treatment.
- Use the same rules and level of discipline as before the cancer diagnosis and treatment.
- Ask your child to continue doing regular chores around the house, when able.

are uneasy about a serious illness. These people may act differently or say hurtful or wrong things to someone who has cancer.

You may want to talk with your child’s teachers and school nurse about the disease, treatment, days missed, and any needed changes in activity. You and your family, the doctor, or members of the treatment team can explain your child’s medical condition



and answer questions. Teachers and other school staff may want to use this information to talk with the other students about what to expect when your child returns to school.

If your child cannot return to school right away, a home tutor may be available through the school system to help your child keep up with studies, making it easier to return to school.

Supporting Your Child

Like you, your child is likely to feel uncertain, worried, and afraid at times, but he or she may find it hard to talk about these fears and may behave differently than usual. For example, your child may become loud or bossy, be quieter than usual, have nightmares, have changes in eating habits, not do as well in school, or go back to earlier behaviors such as bedwetting or thumbsucking.

These common behavior changes are just a few of the ones you may see. You may want to talk about such changes with the doctor, nurse, social worker, teachers, and school counselor, who have had experiences like yours.

Teenagers who have cancer have special concerns. They frequently complain that their parents try to protect them too much. Teenagers are at a stage in their lives when they are naturally trying to be their own bosses and do things for themselves, but having cancer forces them to depend on you. Giving teenagers a chance to make their own decisions and choices, when possible, will help.

You

Your child's illness will bring many changes to your life. To help you cope with these changes, you may want to consider the following suggestions:

- **Make time for yourself.** Try to do some of the things you did before your child got sick. Do not feel guilty that you need some time for yourself. Also, make a special effort to find private times to talk with your partner or those who are close to you. Do not let all your talk be about your child with cancer.
- **Prepare yourself for a lot of waiting.** Find ways to make waiting during clinic visits or while in the hospital less frustrating. Take something to read or do while your child is asleep or does not need your attention.

- **Turn to treatment staff or other resources for support.** Treatment centers have trained staff who can talk with you about your concerns. Make use of these people for support.
- **Contact support groups.** Your treatment center can provide names of support groups at which you can meet with other parents of children who have cancer. Community resources can provide support and information. They can tell you how other parents have dealt, or are dealing, with the same types of situations you are facing.
- **Share the care of your child with your partner or others close to the family.** For example, if your child is in the hospital for a long stay, you and your partner, or friends or relatives, may want to take turns staying with your child. Letting them help will not only give each of you a break from the hospital, but it will help keep you from growing apart when one becomes more involved than the other in your child's treatment.

Brothers and Sisters

The lives of children who have a brother or sister who has cancer change a great deal. Siblings may have many different feelings about the brother or sister who has cancer and the extra attention the child receives. They may feel sorry for their sibling who is ill. Younger children may feel that they caused the cancer. Or they may believe that their own needs are being ignored.

When a child is in the hospital and is very ill, the focus is on that child. As a parent, you may not be able to pay as much attention to your other children as you did before. You may have to miss many of their special school or sports events. You may also use up all your energy and patience caring for your child who has cancer and not have enough energy or time to talk with your other children, play with them, or help them with their homework. It is natural, then, for siblings to be annoyed at the attention your child who has cancer is receiving.

As a result, siblings' behavior may change. They may become depressed, have headaches, or begin to have problems in school. School counselors and support groups may be able to offer you helpful advice for dealing with these issues. In addition, here are some things you can do to help your other children:

- **Talk with them about their feelings.** Talk with them about the special attention your child who has cancer is getting. Let them know that feeling mad is natural. Try to explain what is happening and why you may not be around as much as you were before.
- **Talk with them about the cancer, the treatment, and care.** Younger children's fears can be helped by knowing they couldn't have caused the illness by wishing or by spreading germs from a cold. Treatment and procedures should be explained as being helpful things and not punishments.
- **Spend time with your other children.** Try to spend some time with them doing the things they like.
- **Encourage them to take part in outside activities.** Make a point of noticing and praising what they do in these activities.
- **Involve them in their brother's or sister's treatment.** Let them come along with you to the clinic or hospital. Having them along will allow them to see for themselves what the hospital, clinic, and treatment are like.
- **Talk with them about questions their schoolmates and friends may ask.** Help them think of possible questions and answers so that they will feel comfortable talking about their brother's or sister's illness.
- **Ask other family members and friends to spend time with the other children in the family.** For example, an aunt or uncle might go to school events or attend important games or performances. A neighbor might help them with homework or take them on outings.



Family and Friends

A diagnosis of cancer affects not only the child, parents, and siblings, but also grandparents, other relatives, and friends. These people can support and assist you during this time.

Your employers also may need to be told about your child's illness, so they will know why you are asking for extra time off from work. If needed, your child's doctor can write your employer to explain the situation.

You may need to tell people how to help you. Here are some ideas on how to tell them:

- Be open and honest.
- Take the lead to show others how you and your child want to be treated.
- If they are giving you too much attention, point it out.

- You may find it tiring to have to repeat details about your child’s illness to many family members and friends. Ask one person to handle calls and questions. Or, you can leave short messages on a home answering machine.
- It can be helpful to ask one friend or family member to be the “point person” to share with people your needs—for example, getting the wash done or shopping for groceries.

Financial and Insurance Issues

If you are like most parents of children who have cancer, you will be worried about the costs of treatment and continuing care. You want the best care but are afraid of the costs and how they will be met. You may not have health insurance. Or insurance may not cover all costs. Some insurers will not cover certain costs when a new treatment is under study.

You will need to understand the coverage that your policies offer. Here are some tips for making the most of your insurance:

- Get copies of your insurance policies and find out exactly what is covered.
- Get help if you need it to understand the policy or how to file claims if you need to. Do not be afraid to ask friends, family members, or a social worker for help. Private companies and some community organizations also offer help to deal with insurance.
- Keep careful records of all expenses and claims. Store bills and insurance forms together to make it easier at tax time.
- File claims for all covered costs. Sometimes, people do not take full advantage of their insurance, either because they do not know about a benefit or are put off by the paperwork.
- If your claim is turned down, file again. Ask your doctor to explain to the company why the services should be covered under your policy. If you are turned down again, find out if the company has an appeals process.

What Does the Future Hold?

Because of better research and treatment, children who have cancer are living longer than they used to, and their quality of life is better. Although they lead normal lives, survivors of cancer have some concerns that other people may not have. For example, they must take extra-special care of their health and may have problems obtaining insurance.

Ongoing Health Care

Regular exams are very important after treatment for cancer. At these visits, your child receives both the health care needed by anyone your child's age and special care based on the type of cancer and treatments and current health.

In general, parents of children who have had cancer treatment should do the following.

- **Schedule regular checkups.** Children who have been treated for cancer usually return to the doctor every 3 to 4 months at first, and once or twice a year later on. Ask the doctor how often your child needs to return for followup exams.
- **Be alert to signs of the possible return of cancer.** Doctors have no way to tell for sure whether your child's cancer will return. If it does return, it could be weeks, months, or years after treatment ends. Talk with your child's doctor and treatment team about the chances of cancer returning and the signs of cancer's return.
- **Be alert to signs of lasting effects of cancer treatment.** Cancer treatment may cause side effects many years later. Some cancer treatments may affect your child's ability to have children in the future; affect how your child learns and grows physically; or increase your child's risk of developing a second type of cancer.

- **Be tuned in to any problems your child may have in dealing with feelings about having had cancer, even years after treatment has ended.** Once all the activity of treatment is over, some children suddenly fully realize what happened to them. It can be a very upsetting. At this point, they may need to talk about their feelings and may even need to see a counselor.
- **Promote good health habits.** Eating well and getting enough sleep and exercise will help your child feel better and be healthy.

To better understand your child's health care needs today and in the future, ask the doctor and treatment team.

You need information to continue to take care of your child's health. As your child gets older, he or she also will need this information. You may want to ask the doctor and treatment team the following questions:

- How often should my child have checkups?
- What are the signs of cancer's return or of long-term effects? How likely are they to occur?
- What changes may occur that are not danger signs?
- What kind of diet should my child follow?
- What are the choices for handling chronic pain, the return of cancer, or the long-term effects of therapy?
- What is the best way for me to talk with you about future concerns? (By phone? At a special appointment? At a regular office visit scheduled in advance to allow more time?)
- Who else is available to talk about specific problems?

Insurance Issues in the Future

Another concern of parents is what happens to health insurance coverage and costs after your child has had treatment for cancer. Your child is likely to continue to be covered under your current insurance, but you may have to pay more. If you change jobs or apply for a new policy, however, you may have trouble getting the new coverage for your child, and it may cost more. Older teenagers who may soon be leaving home and looking for a job need to pay special attention to insurance needs. Going off their parent's insurance will mean finding coverage on their own.

One key to making sure your child has insurance coverage is to ask the right questions before changing jobs and look at what your health insurance coverage will include if you change policies.

What Care Is Available When the Cancer Cannot Be Cured?

Although treatments work for many children who have cancer, they do not work for all. If your child's disease cannot be cured or controlled, you may want to think about where your child would be most comfortable—in the hospital, at home, or in a homelike setting. Talk with your child's treatment team about the different choices available to you and your family. It is important to talk with your child about what he or she would like. If your child is too young to speak or does not understand, make a choice based on what you think your child might want.

Special machines and treatments that can help someone live longer and more comfortably are often an accepted part of treating a severe illness. For this reason, many children with terminal cancer and their families choose hospital care. They want to know that everything in the hospital is available to them. More and more cancer patients and their families, however, are choosing care outside of the hospital. As a parent, it is important to know that, with the help of nurses, doctors, and other health professionals, your child can receive good care outside the hospital.

Home Care

Home care is a good choice for many children who have cancer. Home health care professionals can provide cancer drugs, pain medications, equipment such as hospital beds or wheelchairs, proper nutrition, physical therapy, and many complicated nursing and medical care procedures. They also provide emotional support for you and your child and for brothers, sisters, and other family members.

Some people choose home care because hospital care can seem cold. Another advantage of home care is that family and friends, including your child's friends, can support and help you. Home care involves bringing members of the home health care team into your house or possibly into the home of a relative or friend. Depending on the needs and concerns of your child and your family, the home health team may include all or many of the following professionals: nurses or nurse practitioners, social workers, dietitians, physical therapists, pharmacists, oncologists, radiation therapists, clergy, and a psychologist or psychiatrist. Home health aides also are available to help with bathing, personal care, or preparing light meals, as needed. In many cases, specially trained volunteers, called respite care workers, can care for your child when you need a few hours away from home.

You, your family, and, when possible, your child, will work closely with health care workers to make sure that your child is comfortable and receives the best care possible. If 24-hour care is needed, members of the team will work different shifts to give you and your child around-the-clock support.

Home care is given through various for-profit and not-for-profit private agencies, public and private hospitals, and public health departments. Your child's treatment team can give you information on home health care.

Hospice Care

Hospice programs provide special care for cancer patients and their families, either at home or away from home, in separate buildings, or within hospitals. A team of medical professionals and volunteers works with the family and patient. The main concerns of hospice caregivers are quality of life and control of pain.

Hospice caregivers also help family members learn how to care for children who have terminal cancer. They give emotional, social, and spiritual support during your child's illness and after your child dies.

About 1,800 hospice programs across the country offer total hospice care. The National Hospice and Palliative Care Organization encourages and tracks the quality of hospice care. Children's Hospice International advocates for hospice care for children. You can find more information about these organizations by calling the NCI-supported Cancer Information Service (CIS) at 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615.

Day-to-Day Concerns

During the past several years, health care professionals have become more aware of the needs of children who have late-stage cancer and of their families. For example, attending school half-days or even for an hour a day—if possible—may make your child happier. Talking with your child about death and dying and giving your child as many choices as possible shows your child that you are being open and honest, and shows your support, love, and respect. Paying close attention to changes in your child's behavior may give you important clues as to what your child needs and whether he or she wants to talk about dying. Including all of your children in everyday activities—such as reading, doing homework, or watching a favorite television program or video together—can help keep the family close.

Resources

Information about cancer is available from many sources, including the ones listed here. You may want to check for more information at your local library, at bookstores, or from support groups in your community.

National Cancer Institute Information Resources

You may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

Telephone...

Cancer Information Service (CIS)

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Internet...

<http://cancer.gov>

NCI's primary Web site; contains information about the Institute and its programs, cancer information, and clinical trials.

Fax...

CancerFax®

Includes NCI information about cancer treatment, screening, prevention, and supportive care. To obtain a contents list, dial 1-800-624-2511 or 301-402-5874 from your touch-tone phone or fax machine handset and follow the recorded instructions.

For Additional Information

The Children's Oncology Group

The Children's Oncology Group (C.O.G.) was formed by the merger of the four national pediatric cancer research organizations: the Children's Cancer Group, the Intergroup Rhabdomyosarcoma Study Group, the National Wilms' Tumor Study Group, and the Pediatric Oncology Group. The primary objective of the organization is to conduct clinical trials of new therapies for childhood cancers. Pediatric clinical trials are conducted across the country.

The C.O.G. Web site is

http://www.nccf.org/NCCF/AboutCCG/COG_who.htm

Other Booklets

The National Cancer Institute booklets listed below can be obtained from the NCI-supported Cancer Information Service (CIS) by calling 1-800-4-CANCER (1-800-422-6237) or TTY at 1-800-332-8615. Also, many NCI publications may be viewed or ordered at <http://cancer.gov/publications>.

Booklets About Cancer, Cancer Treatment, and Side Effects

- Chemotherapy and You: A Guide to Self-Help During Treatment
- Eating Hints for Cancer Patients
- El dolor relacionado con el cáncer
- El tratamiento de radioterapia: guía para el paciente durante el tratamiento
- Get Relief from Cancer Pain
- La quimioterapia y usted: Una guía de autoayuda durante el tratamiento del cáncer
- Radiation Therapy and You: A Guide to Self-Help During Treatment
- Taking Part in Clinical Trials: What Cancer Patients Need To Know



- **Pain Control: A Guide for People With Cancer and Their Families**
- **Understanding Cancer Pain**
- **What You Need To Know About...**
(This is a series of booklets. Each provides information about a specific type of cancer, including symptoms, diagnosis, treatment, emotional issues, and questions to ask the doctor. Some are available in Spanish.)

Booklets About Living with Cancer

- **Facing Forward**
- **Taking Time: Support for People With Cancer and the People Who Care About Them**
- **When Cancer Recurs: Meeting the Challenge Again**
- **Advanced Cancer: Living Each Day**

Appendix

Common Childhood Cancers		
Type	Description	Age
LEUKEMIAS		
All leukemias	Leukemia is cancer of the blood cells. In acute leukemia, the disease comes on suddenly and gets worse quickly if it is not treated. Most childhood leukemias are acute. Chronic leukemia is usually milder at the start and gets worse more slowly.	
Acute lymphoblastic leukemia (ALL)	Also known as “childhood leukemia” because it is the most common childhood cancer.	Usually occurs between 2 and 8 years old.
Acute myelogenous leukemia (AML)	Also called acute non-lymphatic leukemia.	Usually occurs in people over age 25, but sometimes affects teenagers and children.
Chronic myelogenous leukemia (CML)	CML is a slowly progressing disease in which too many white blood cells are made in the bone marrow. Also called chronic myeloid leukemia or chronic granulocytic leukemia.	Sometimes occurs in adolescents but almost never affects children. Most commonly affects adults. Five percent of childhood leukemias are CML.

Common Childhood Cancers (continued)

Type	Description	Age
LYMPHOMAS		
All lymphomas	Lymphoma is a tumor of the lymph tissue. Because lymph tissue is in many parts of the body, lymphomas can start almost anywhere.	
Hodgkin's disease	Hodgkin's disease is a cancer that tends to affect the lymph nodes that are close to the body's surface, such as those in the neck, armpit, or groin area.	Occurs mainly in young adults and in people over age 65 but can affect teenagers and children. Lymphomas are the third most common childhood cancer. Rare under age 5.
Non-Hodgkin's lymphoma	In children, non-Hodgkin's lymphoma affects lymph nodes that are found deeper in the body. The bowel is the most frequent spot, often in the area next to the appendix, or in the upper part of the chest.	Occurs most often in ages 10 to 20. Unusual under age 3.
Burkitt's lymphoma	A type of non-Hodgkin's lymphoma. In Americans, the usual site is the abdomen.	Age range is 2–16 years

Common Childhood Cancers (continued)

Type	Description	Age
BONE CANCERS		
Osteosarcoma or osteogenic sarcoma	Osteosarcoma is the sixth most common malignancy in children and the most common type of bone cancer in children. Usually affects the thigh bone (femur), upper arm bone (humerus), or one of the long bones of the lower leg (tibia).	Occurs between ages 10 and 25.
Ewing's sarcoma	The most common sites for Ewing's sarcoma are the hipbones, long bones in the thigh (femur) and upper arm (humerus), and ribs.	Occurs between ages 10 and 25.
Chondrosarcoma	Chondrosarcoma forms in cartilage, the rubbery tissue around the joints.	Found mainly in adults, although it can occur in children.
LIVER CANCERS		
All liver cancers	Also called hepatoma, liver cancer is a rare disease. When the tumor is just in the liver and can be removed with surgery, it is highly curable. Two types of cancer can start in the liver and are identified by how they look under the microscope.	

Common Childhood Cancers (continued)

Type	Description	Age
LIVER CANCERS (continued)		
Hepatoblastoma	Hepatoblastoma can be inherited.	Usually occurs before age 3.
Hepatocellular cancer	Children infected with hepatitis B or C (viral infections of the liver) are more likely to get this type of cancer.	Occurs most often in children age 4 or younger and those between ages 12 and 15.
SOFT TISSUE SARCOMAS		
All soft tissue sarcomas	These sarcomas start in soft tissues, which connect, support, and surround body parts and organs.	
Rhabdomyosarcoma	Rhabdomyosarcoma is the most common type of soft tissue sarcoma. It starts in muscle tissue and can occur anywhere in body. It is most often found in the head and neck, kidneys, bladder, arms, legs, and trunk.	Affects children ages 2 to 6 years old.

Common Childhood Cancers (continued)

Type	Description	Age
OTHER CANCERS		
Brain cancer	Brain cancer is the most common solid tumor cancer in childhood. The most common brain tumors are called gliomas; there are several types of gliomas.	Occurs most often in children from birth to 15 years old.
Wilms' tumor or nephroblastoma	This type of cancer starts in the kidney. It is the most common type of kidney cancer in children but is very different from kidney cancer in adults. May be hereditary.	Age range 6 months to 10 years—greatest in first 5 years.
Neuroblastoma	Cancer of certain nerve cells of the body is called neuroblastoma. The second most common solid tumor cancer in children, it usually starts in abdomen, either in the adrenal glands (located just above kidneys in back of the upper abdomen) or around the spine. It can also start around the spinal cord in the chest, neck, or pelvis.	Occurs most often in babies and very young children.

Common Childhood Cancers (continued)

Type	Description	Age
OTHER CANCERS (continued)		
Retinoblastoma	Retinoblastoma is cancer of the eye. It affects the retina, a thin membrane in the back of eye that works like a camera, making a picture of what we see. Some children have retinoblastoma that runs in families. It usually occurs in only one eye, but sometimes affects both eyes.	Occurs mostly in children younger than 5 years old.

Dictionary

The definitions below are based on those found in the National Cancer Institute's CancerNet dictionary, which is available online at <http://www.cancernet.nci.nih.gov/dictionary.html>.

angiogram (AN-jee-o-gram): An x-ray of blood vessels; the person receives an injection of dye to outline the vessels on the x-ray.

antigens: Substances that cause the immune system to make a specific immune response.

benign (beh-NINE): Not cancerous; does not invade nearby tissue or spread to other parts of the body.

biological response modifier (by-o-LAHJ-i-kul): (BRM) A substance that stimulates the body's response to infection and disease.

biological therapy (by-o-LAHJ-i-kul): Treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also used to lessen side effects that may be caused by some cancer treatments. Also called immunotherapy or biological response modifier (BRM) therapy.

biopsy (BY-ahp-see): A procedure used to remove cells or tissues in order to look at them under a microscope to check for signs of disease. When an entire tumor or lesion is removed, the procedure is called an excisional biopsy. When only a sample of tissue is removed, the procedure is called an incisional biopsy or core biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy or fine-needle biopsy.

bone marrow: The soft, sponge-like tissue in the center of bones that produces white blood cells, red blood cells, and platelets.

bone marrow aspiration (as-per-AY-shun): The removal of a small sample of bone marrow (usually from the hip) through a needle for examination under a microscope.

bone marrow biopsy (BY-ahp-see): The removal with a needle of a sample of tissue from the bone marrow for examination under a microscope.

bone marrow transplantation (trans-plan-TAY-shun): A procedure to replace bone marrow damaged by cancer or by treatment with high doses of anticancer drugs or radiation. Transplantation may be autologous (the person's marrow saved before treatment), allogeneic (marrow donated by someone else), or syngeneic (marrow donated by an identical twin).

cancer: A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

carcinoma (kar-sin-O-ma): Cancer that begins in the skin or in tissues that line or cover internal organs.

catheter (KATH-i-ter): A flexible tube used to deliver fluids into or withdraw fluids from the body.

CBC (complete blood count): A test to check the white blood cells, hemoglobin, hematocrit, platelet count, and reticulocyte count in a sample of blood.

chemotherapy (kee-mo-THER-a-pee): Treatment with anticancer drugs.

child-life worker: A professional worker who helps children cope better with being in the hospital and getting treatment by arranging play therapy, schoolwork, and other activities.

clinical trial: A research study that evaluates the effectiveness of new interventions in people. Each study is designed to evaluate new methods of screening, prevention, diagnosis, or treatment of a disease.

colony-stimulating factors: Proteins that cause the bone marrow to develop different types of blood cells.

combination chemotherapy: Treatment using more than one anticancer drug.

combination therapy: Treatment using more than one therapy—such as chemotherapy, surgery, radiation immunotherapy—to treat the cancer.

culture: A lab test used to find and identify the type of infection. Bacteria in blood samples or other body samples are made to grow in a special substance so that they can be studied.

cytokines: Proteins formed in small amounts by all human cells to help control the working of cells.

CT scan: computerized tomography scan. A series of detailed pictures of areas inside the body: The pictures are created by a computer linked to an x-ray machine. Also called computerized axial tomography or CAT scan.

distraction: Doing an activity that takes one's mind off the pain or helps one to relax. Some examples of activities are painting, doing a puzzle, or working on a craft.

guided imagery: Using your imagination to create a picture in the mind, like a daydream. It can be used to help relax or take your mind off of the pain or a procedure.

hypnosis: A trance-like state that is similar to sleep, but the person can talk and hear. This state can be brought on by a person trained as a hypnotist, or it can be self-induced. Hypnosis can be used to ease pain.

immune system (im-YOON): The complex group of organs and cells that defends the body against infection or disease.

immunotherapy (IM-yoo-no-THER-a-pee): Treatment to stimulate or restore the ability of the person's immune system to fight infection and disease. Also used to lessen side effects that may be caused by some cancer treatments. Also called biological therapy or biological response modifier (BRM) therapy.

infection: A condition in which germs enter the body and cause fever and illness.

informed consent: Written permission given before surgery, research, or other kinds of treatments or tests. The patient or a parent or guardian must understand the treatment and legally agree to any risks involved.

interferon: A type of cytokine that helps the immune system slow the rate of growth and division of cancer cells.

interleukins: A type of cytokine made by a type of white blood cell called a lymphocyte.

intramuscular (IM): Injecting a drug into a muscle. The drug is then absorbed into the bloodstream.

intrathecal (in-tra-THEE-kal): (IT) The thin space beneath the lining of the spinal cord and brain.

intravenous (in-tra-VEE-nus): (IV) Injected into a vein.

leukemia (loo-KEE-mee-a): Cancer of the blood-forming tissue.

local therapy: Treatment that affects cells in the tumor and the area close to it.

lumbar puncture: The insertion of a needle into the lower part of the spinal column to collect cerebrospinal fluid or to give anti-cancer drugs intrathecally. Also called a spinal tap.

lymph (limf): The almost colorless fluid that travels through the lymphatic system and carries cells that help fight infection and disease.

lymph node: A rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. Also known as a lymph gland. Lymph nodes are spread out along lymphatic vessels and contain many lymphocytes, which filter the lymphatic fluid (lymph).

lymphangiogram (lim-FAN-jee-o-gram): X-rays of the lymphatic system. A dye is injected into a lymphatic vessel and travels throughout the lymphatic system. The dye outlines the lymphatic vessels and organs on the x-ray.

lymphatic system (lim-FAT-ik): The tissues and organs that produce, store, and carry white blood cells that fight infection and other diseases. This system includes the bone marrow, spleen, thymus, and lymph nodes and a network of thin tubes that carry lymph and white blood cells. These tubes branch, like blood vessels, into all the tissues of the body.

lymphoma (lim-FO-ma): Cancer that arises in cells of the lymphatic system.

malignant (ma-LIG-nant): Cancerous; a growth with a tendency to invade and destroy nearby tissue and spread to other parts of the body.

metastasize (meh-TAS-ta-size): To spread from one part of the body to another. When cancer cells metastasize and form secondary tumors, the cells in the metastatic tumor are like those in the original (primary) tumor.

metastatic cancer: Cancer that has spread from the place in which it started to other parts of the body.

monoclonal antibodies (MAH-no-KLO-nul AN-tih-BAH-deez): Laboratory-produced substances that can locate and bind to cancer cells wherever they are in the body. Many monoclonal antibodies are used in cancer detection or therapy; each one recognizes a different protein on certain cancer cells. Monoclonal antibodies can be used alone, or they can be used to deliver drugs, toxins, or radioactive material directly to the tumor.

MRI: Magnetic resonance imaging (mag-NET-ik REZ-o-nance IM-a-jing). A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.

nerve blocks: A method in which medicine is injected into or around a nerve to numb or deaden the nerve fibers to give temporary relief of pain.

nuclear scans: A procedure in which a radioactive substance is swallowed or is injected into a vein. The substance collects in areas of the body where cells are dividing rapidly, a condition typical of cancer cells. Pictures are then taken that show the amounts of radioactivity that has collected in the organ being examined. Larger or smaller amounts of radioactivity may mean that cancer or other disorders are present.

oncologist (on-KOL-o-jist): A doctor who specializes in treating cancer.

oncology nurse: A nurse who specializes in treating and caring for people who have cancer.

pathologist (pa-THOL-o-jist): A doctor who identifies disease by studying cells and tissues under a microscope.

pediatric (pee-dee-AT-rik): Having to do with children.

peripheral blood stem cell transplant: A method of replacing blood-forming cells destroyed by cancer treatment. Immature blood cells (stem cells) in the circulating blood that are similar to those in the bone marrow are given after treatment to help the bone marrow recover and continue producing healthy blood cells.

physical therapy: Teaching a person to perform skills that were done before an illness or accident, or how to use an artificial limb.

plasma (PLAZ-ma): The clear, yellowish, fluid part of the blood that carries the blood cells. The proteins that form blood clots are in plasma.

platelets (PLAYT-lets): A type of blood cell that helps prevent bleeding by causing blood clots to form. Also called thrombocytes.

prosthesis (pros-THEE-sis): An artificial replacement of a part of the body.

prosthetist (PROS-theh-tist): A person skilled in making artificial limbs

protocol: A detailed plan a doctor follows in treating a cancer patient. Different cancer patients have different protocols. Protocols are used in both clinical trials and standard therapy.

radiation therapy (ray-dee-AY-shun): The use of high-energy radiation from x-rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy) or from material called radioisotopes. Radioisotopes produce radiation and are placed in or near a tumor or near cancer cells. This type of radiation treatment is called internal radiation therapy, implant radiation, or brachytherapy. Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Also called radiotherapy.

radioisotope: An unstable element that releases radiation as it breaks down. Radioisotopes can be used in imaging tests or as a treatment for cancer.

recurrence: The return of cancer, at the same site as the original (primary) tumor or in another location, after it had disappeared.

red blood cells: (RBCs) A type of cell that carries oxygen to all parts of the body. Also called erythrocytes.

relaxation therapy: Using relaxation methods to help ease pain and feel more relaxed.

remission: Disappearance of the signs and symptoms of cancer. When this happens, the disease is said to be “in remission.” A remission may be temporary or permanent.

sarcoma (sar-CO-muh): A cancer of the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

solid tumor: Cancer of body tissues other than blood, bone marrow, or the lymphatic system.

spinal tap: A test in which a fluid sample is removed from the spinal column with a thin needle. Also called a lumbar puncture.

staging: Doing exams and tests to learn the extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of the body.

standard therapy: A currently accepted and widely used treatment for a certain type of cancer, based on the results of past research.

subcutaneous (sub-kyoo-TAY-nee-us): Beneath the skin.

supportive care: Treatment given to prevent, control, or relieve complications and side effects and to improve the person's comfort and quality of life.

surgery: A procedure to remove or repair a part of the body or to find out if disease is present.

systemic (sis-TEM-ik): Affecting the entire body.

systemic therapy: Treatment that uses substances that travel through the bloodstream, reaching and affecting cells all over the body.

tissue (TISH-oo): A group or layer of cells that together perform specific functions.

tumor (TOO-mer): An abnormal mass of tissue that results from excessive cell division. Tumors perform no useful body function. They may be either benign (not cancerous) or malignant (cancerous).

tumor marker: A substance sometimes found in an increased amount in the blood, other body fluids, or tissues, and which may mean that a certain type of cancer is in the body. Examples of

tumor markers include CA 125 (ovarian cancer), CA 15-3 (breast cancer), CEA (ovarian, lung, breast, pancreas, and gastrointestinal tract cancers), and PSA (prostate cancer). Also called biomarker.

ultrasound test: A test that bounces sound waves off tissues and internal organs and changes the echoes into pictures (sonograms).

white blood cell: A type of cell in the immune system that helps the body fight infection and disease. White blood cells include lymphocytes, granulocytes, macrophages, and others.

x-ray: High-energy radiation used in low doses to diagnose diseases, and in high doses to treat cancer.

The National Cancer Act, passed by Congress in 1971, made cancer research a national priority. Since that time, the National Cancer Institute (NCI), the lead Federal agency for cancer research, has collaborated with top researchers and facilities across the country to conduct innovative research leading to progress in cancer prevention, detection, diagnosis, and treatment. These efforts have resulted in a decrease in the overall cancer death rate, and have helped improve and extend the lives of millions of Americans.

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