

Children's Oncology Group

FAMILY HANDBOOK

CureSearch
for
Children's Cancer

**CHILDREN'S
ONCOLOGY
GROUP**

The world's childhood
cancer experts

THE CHILDREN'S ONCOLOGY GROUP

*Family Handbook for
Children with Cancer*

Second Edition

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The world's childhood
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for
Children's Cancer

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THE CHILDREN'S ONCOLOGY GROUP

Family Handbook for Children with Cancer

SECOND EDITION

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*"The influence of each human being on others in this life is a kind of immortality."
—John Quincy Adams*

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SINCERE APPRECIATION TO:**

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Dear Parents and Families,

As a parent or family member of a child recently diagnosed with cancer, we know that you are struggling with this difficult news. While we cannot take away the pain you feel right now, we hope this Family Handbook can provide you with important medical information that helps make these difficult times a little bit easier.

The Family Handbook was developed and produced by the Children's Oncology Group and CureSearch for Children's Cancer to help you. In it, you will find articles and images about the many medical tests, procedures, treatment options, and possible hospitalizations your child will experience. There is also a glossary of terms for your reference and review.

Understanding and adapting to the world of health care is challenging. As you seek more information, please visit our website at www.curesearch.org. Written by the very doctors and nurses who care for children with cancer each and every day, the site contains not only information about diagnosis and treatment, but also about the emotional aspects of caring for a child with cancer.

CureSearch was able to fund the handbook and website through philanthropic efforts. It is with the partnership of hospitals, clinicians, patients, and families that we are able to raise money to provide the support needed to guide families through their cancer journey and fund research that we believe will ultimately lead to a cure for all children with cancer.

Sincerely,



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An Introduction to the Family Handbook for Children with Cancer

If you have received this handbook, then you most likely have recently learned that your child, or a child you care about, is being evaluated for or may have cancer. We know that you have many questions and may be feeling overwhelmed. That is why the Children's Oncology Group (COG) developed this handbook, which provides reliable information about treatment, support, and follow-up care for children and young people with cancer.

Fortunately, the outlook for most children diagnosed with cancer is promising. This is because of the great progress made through research, including clinical trials conducted by the Children's Oncology Group. You can find out more about clinical trials and the Children's Oncology Group in this handbook and from your child's treatment team.

We encourage you to review the information in this handbook and discuss it with your child's health care providers. They can help you to customize this book by adding more information about your child's illness and treatment, and about the hospital. By working together with your child's doctors, nurses, and other health care providers, you can help make sure that your child gets the best possible care.

Please feel free to share this information with family members and friends who may want to learn more about your child's illness, treatment, and care. The more they know, the more they can assist you, your child and family during this challenging time.

We hope that this handbook will be a helpful source of information and support for you throughout your child's treatment.



Wendy Landier, RN, PhD
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Information from My Hospital

NOTE TO PARENTS AND FAMILIES

This section of the *Children's Oncology Group Family Handbook for Children with Cancer* is designed to provide you with information about your child's illness and treatment, and about your hospital. Ask your health care providers to help customize this section of the handbook to meet your specific needs.

DISCLAIMER: MATERIALS IN THIS "INFORMATION FROM MY HOSPITAL" SECTION OF THE HANDBOOK ARE PROVIDED BY THE HEALTH CARE TEAM AT YOUR HOSPITAL, TREATMENT CENTER, OR CLINIC. THE CHILDREN'S ONCOLOGY GROUP AND CURESEARCH FOR CHILDREN'S CANCER DO NOT ASSUME RESPONSIBILITY FOR THE OPINIONS EXPRESSED OR THE INFORMATION CONTAINED IN THE "INFORMATION FROM MY HOSPITAL" SECTION OF THIS HANDBOOK.

INSTRUCTIONS FOR INSTITUTIONS

This handbook is designed to provide information for families at Children’s Oncology Group (COG) institutions. The content provides a broad foundation for patient/family education and has been approved by the COG leadership for use across institutions. Modification of handbook content is prohibited, including deleting, editing or adding to the text. However, to maximize the usefulness of this resource for patients and families, this “Information from My Hospital” section allows institutions to customize the COG Family Handbook for their patients and families by adding supplementary content, such as details about diagnosis and treatment. COG also encourages inclusion of the following institution-specific information in this section:

- Introductory information about your institution, including visiting policies
- Important phone numbers/when to call for help
- Health care team members at your institution
- Information about your institution’s outpatient clinic
- Local/community resources
- Information specific to the following at your institution:
 - Diagnostic procedures (e.g., imaging)
 - Safe handling of chemotherapy
 - Fever guidelines
 - How to contact the health care team, including at night and on weekends/holidays
 - Services available (social work, chaplain, housing, parking, etc.)
 - Chickenpox/Shingles
 - Blood transfusions
 - Low platelet counts
 - Mouth care
 - Central line care

Throughout this handbook, families are cued to refer to this “Information from My Hospital” section of the handbook for institution-specific information.

Note: Institutions may remove this page prior to distributing this handbook to patients/families.

IF YOU HAVE ANY COMMENTS OR SUGGESTIONS ABOUT THE COG FAMILY HANDBOOK, PLEASE CONTACT PRODUCTION@CURESEARCH.ORG OR CALL 800-458-6223.

When to Call for Help



Sometimes children with cancer will have symptoms that are warning signs of a serious condition. Your health care team considers these symptoms a sign of an emergency. An emergency means that you must take action right away.

Call Emergency Services (“911” in the U.S. and Canada) immediately if your child:

- is not breathing or has severe difficulty breathing
- has skin and lips that look blue
- is having a seizure and you have not been told that these can be managed at home
- does not wake up after you have attempted to awaken them (loss of consciousness)

Call your health care team immediately (do not wait until the clinic or office opens) if your child has:

- fever or chills
- trouble with breathing
- bleeding that does not stop within 5-10 minutes
- a change in behavior or level of consciousness (such as being very sleepy, very irritable, or not making sense when talking)
- a sudden change in vision
- a severe headache
- new weakness of the face, arm, or leg
- uncontrolled pain
- repeated vomiting or diarrhea
- the inability to drink fluids
- a break in the central line
- exposure to chickenpox or shingles

Visiting the Emergency Room (ER)/Emergency Department (ED)

If your child's central line breaks or your child has a fever or other emergency, your health care provider may tell you to go to the Emergency Room. When you arrive in the ER, tell the health care provider that your child is being treated for cancer and cannot wait in an area with other children who may be sick, especially if your child's blood counts are low. Tell the ER team what kind of cancer your child has, the date of the last treatment, and the results of the most recent blood counts. Make sure that the ER team knows that your child cannot have an enema, suppository, or rectal temperature. If your child has a fever, they should be seen right away.

If you're planning to use an ER that is not where your child receives their oncology care, ask your health care team for a letter that you can give to the ER team that explains your child's diagnosis and potential needs in the emergency room.

For more information about when to call for help, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG

WHEN TO
CALL FOR HELP

Notes and Questions for Your Health Care Team

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The Hospital

Your Health Care Team

As a parent, you are part of the team that will take care of your child. Depending on your child's needs and the staff at your hospital and/or clinic, any of the following people may be part of your health care team.

ATTENDING PHYSICIAN

A doctor who has completed medical school and further training in residency and fellowship and now specializes in cancer care. The attending physician directs and supervises the medical care of your child.

CHAPLAIN

A person who is trained to offer spiritual care, support and prayer according to each family's individual needs.

CHILD LIFE SPECIALIST

A person who has special training in child development and how children react to illness and being in the hospital. A child life specialist helps children to cope with cancer and its treatment.

CLINICAL NURSE SPECIALIST/ NURSE PRACTITIONER

A nurse who has completed an advanced degree program and specialty training in caring for children with cancer. The nurse practitioner or clinical nurse specialist may coordinate the medical and nursing care of your child.

CLINICAL RESEARCH ASSOCIATE

A person who is trained to keep track of data related to your child being enrolled and treated on a clinical trial.

DIETITIAN

A person who is trained to evaluate your child's nutritional needs and weight. The dietitian also helps to provide teaching and support about eating and drinking when your child goes home.



FELLOW

A doctor who has completed medical school and a residency and is now receiving specialty training in pediatric hematology, oncology, and/or hematopoietic stem cell transplant.

HOUSE OFFICER/RESIDENT

A doctor who has completed medical school and is now receiving specialty training.

MEDICAL STUDENT

A college graduate who is receiving training to become a doctor.

NURSE

A person who is trained to care for patients during illness and to assist them in regaining and maintaining health. Nurses provide daily nursing care and health education to children and their families in the hospital or clinic.

PALLIATIVE CARE TEAM

The palliative care team includes doctors, nurses, social workers, chaplains, and other professionals who work with the health care team to ease symptoms and provide support for children with serious illness and their families. For more information about palliative care, see page 59.

PHARMACIST

A person who is trained to prepare the medicines and nutritional support that your child will need. The pharmacist may also explain how medicines are to be given.

PHYSICAL/OCCUPATIONAL/SPEECH THERAPIST

A person who works with your child to maintain or restore a level of fitness and the ability to perform activities of daily living, or helps with improving speech.

PHYSICIAN ASSISTANT

A person who is trained to assist the physician in coordinating and providing your child's medical care.

PSYCHIATRIST/PSYCHOLOGIST

A doctor or trained specialist who is available to help you and your child cope with feelings. This person may also perform testing to see if your child has learning problems.

SCHOOL TEACHER/LIAISON

A teacher who works in the hospital to help your child keep up with school work during the hospital stay. The teacher can also keep in touch with your child's teacher at home.

SOCIAL WORKER

A person who is trained to help you and your child cope with illness and hospitalization through counseling, support groups, financial assistance, and resource referral.

VOLUNTEER

An unpaid person who is trained to help with non-medical activities.

For more information about your health care team members, refer to the “Information from My Hospital” section of this handbook, or ask your health care team.

Daily Routine When Your Child is Admitted to the Hospital

VITAL SIGNS

Your child’s blood pressure, temperature, heart rate, and breathing rate will be checked regularly. At times, such as when your child has a fever or needs to get a transfusion, the vital signs will be checked more often. Vital signs help the health care team know how well or ill your child is. For example, a very fast heart rate and a low blood pressure may mean that your child has a serious infection.

WEIGHT

Your child’s weight will be closely monitored. Knowing if your child is losing or gaining weight is important. Weight loss may mean that your child is not eating or drinking enough. In some cases, your child may gain weight from too much fluid or changes in appetite related to treatment. The health care team needs to know when your child’s weight changes during treatment. The dose of chemotherapy may also change if your child’s weight goes up or down.

INTAKE AND OUTPUT

Intake means how much fluid your child is taking in (by mouth and into a vein, also called intravenous or I.V.). Output means how much fluid your child is putting out (urine, vomit, and stool). Intake and Output (I/O) may be measured every day to keep track of what and how much your child drinks, how much I.V. fluid your child receives, and how much your child puts out. If you change your child’s diaper, do not throw it away until it is weighed to see how much urine and/or stool is in the diaper. If your child uses the urinal or bedpan, do not flush the urine or stool in the toilet until it is measured.

BLOOD TESTS

Your child will need to have blood tests done during cancer treatment. Blood tests are often done very early in the morning so that the test results are ready when the health care team makes the plan of care for the day.

ROUNDS

Each day the health care team will examine your child, review information such as vital signs and results of blood tests, and talk with you about the plan of care. This is called rounds. It is helpful to write down any questions you may have before rounds to help you remember what to ask.

Visitors

Anyone who has a fever, rash, diarrhea, vomiting, or other illness should not visit you or your child. Family and friends who may have been exposed to anyone with chickenpox or shingles should not visit the hospital or clinic areas. Visitors may be limited during flu season and for other medical reasons. Check with the health care team for the current visitor information and guidelines in your hospital or clinic.

For more information about visiting policies at your hospital, refer to the “Information from My Hospital” section of this handbook, or ask your health care team.

FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG

About Cancer

What is Cancer?

Cancer is one name for a group of diseases. To understand cancer, you must first understand cells. Cells are the basic building blocks that make up all the tissues and organs in the body. Cells divide to make new cells, and to replace damaged or old cells. Each cell contains genetic material (DNA) that tells the cell when to divide and when to die. Cancer occurs when the DNA becomes damaged and gives the wrong instructions to the cell. The cancer cells grow out of control. Cancer cells divide when they shouldn't and stay alive longer than they should. Cancer cells can crowd out normal cells. A lump of cancer cells is called a tumor. Tumors can be malignant (fast-growing with a tendency to spread) or benign (slow-growing and do not spread).

Types of Childhood Cancer

Each type of cancer has its own name, treatment, and prognosis (chance of responding to treatment). Cancer in children can be divided into three groups.

- **Leukemias** (cancers of the blood-forming cells)
- **Lymphomas** (cancers of the lymphatic system)
- **Solid tumors** (cancers of the bone, muscle, brain, organs, or other tissues in the body)

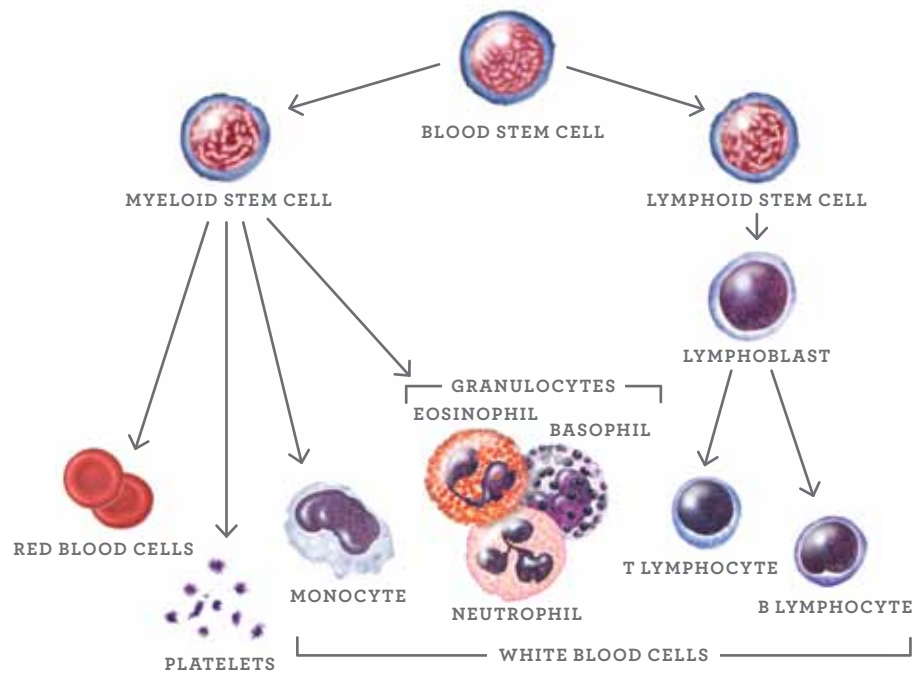
Below is information about some of the more common types of childhood cancer. Your health care team will talk with you about your child's specific type of cancer.

Leukemia

Leukemia is a cancer of the blood-forming cells that are produced in the bone marrow. Bone marrow is found in the center of bones and serves as a blood-making "factory." Three types of blood cells are made in the bone marrow. Red blood cells carry oxygen to the body. White blood cells fight infection. Platelets help stop bleeding.

ACUTE LYMPHOBLASTIC LEUKEMIA (ALL)

Acute lymphoblastic leukemia (ALL) is a cancer involving the blood-forming cells that normally make a type of white blood cell called a lymphocyte. ALL starts when a single young blood-forming cell, called a lymphoblast, develops a series of mistakes



BLOOD CELL DEVELOPMENT

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or mutations that transforms it into a leukemia cell. The leukemia cell multiplies uncontrollably, crowding out healthy cells in the bone marrow. The leukemia cells can also spill out into the bloodstream, and spread to the lymph nodes, spleen, liver, and other organs. Leukemia cells can also spread to the spinal fluid (the fluid that surrounds the brain and spinal cord). These cells can be detected by looking at the spinal fluid through a microscope after doing a lumbar puncture (sometimes called spinal tap). In boys, leukemia cells can also spread to the testicles, causing the testicles to become swollen, but this is uncommon.

There are different types of ALL, named for the type of lymphocyte that is affected. The two major types of lymphocytes are B-cells and T-cells. The most common type of ALL affects B-cell lymphocytes as they are developing. This type of ALL is called precursor-B cell ALL. Another type of ALL affects T-cell lymphocytes as they are developing. This type of ALL is called T-cell ALL. Knowing the type of ALL can be important in guiding treatment.

ALL is the most common type of childhood cancer. About 4 out of every 5 children who have leukemia will have ALL.

ACUTE MYELOID LEUKEMIA (AML)

Acute myeloid leukemia (AML) is a type of cancer involving blood-forming cells called myeloid cells. Myeloid cells include certain types of white blood cells, called

granulocytes and monocytes, as well as red blood cells and platelets. AML begins when a single young blood-forming cell, called a myeloblast, develops a series of mistakes or mutations that transform it into a leukemia cell. The leukemia cell multiplies uncontrollably, crowding out healthy cells in the bone marrow. The leukemia cells can also spill out into the bloodstream, and spread to the lymph nodes, spleen, liver, and other organs. Leukemia cells can also spread to the spinal fluid (the fluid that surrounds the brain and spinal cord). These cells can be detected by looking at the spinal fluid through a microscope after doing a lumbar puncture (sometimes called spinal tap). Occasionally the leukemia cells can form a lump, called a chloroma, that can occur anywhere in the body. There are many different subtypes of AML. Some of the subtypes of AML are myeloblastic, promyelocytic, and monocytic leukemia. Knowing the type of AML can be important in guiding treatment.

About 1 out of every 5 children who have leukemia will have AML.

CHRONIC MYELOID LEUKEMIA (CML)

Chronic myeloid leukemia (CML) is a slow-growing cancer involving the blood-forming cells that make a type of white blood cell called a granulocyte. CML begins when a blood-forming cell develops a change in its genetic code, creating an abnormality known as the Philadelphia chromosome. The Philadelphia chromosome signals the cell to multiply out of control, generating large numbers of abnormal white blood cells. These abnormal white blood cells build up over time and may spread to other parts of the body, including the spleen. Eventually, these abnormal white blood cells may turn into faster-growing types of leukemia cells.

Only about 1 out of every 50 children who have leukemia will have CML.

JUVENILE MYELOMONOCYTIC LEUKEMIA (JMML)

Juvenile myelomonocytic leukemia (JMML) is a rare form of childhood leukemia in which a type of white blood cell, called an immature monocyte, is overproduced by the bone marrow. The large number of immature monocytes crowd out healthy cells in the bone marrow, which can cause fatigue, bleeding, and other symptoms. JMML usually occurs in very young children.

Less than 1 in 100 children who have leukemia will have JMML.

Lymphoma

Lymphoma is a cancer of the lymphatic system. The lymphatic system is an important part of the immune system. Lymphatic tissue is found all over the body—in the lymph nodes, tonsils, adenoids, spleen, thymus gland and inside the bone marrow. Lymphoma begins when a cell of the lymphatic system becomes cancerous through a series of

mutations or mistakes that allows it to multiply uncontrollably. The rapid cell growth leads to enlarged lymph nodes (sometimes called swollen glands) and/or body organs. The symptoms of lymphoma depend on the location of the enlarged lymph nodes and/or organs. Often, the first sign of the illness is a lump or swelling, which might be found in the neck, groin, or under the arm. Sometimes lymphoma cells cause lymph nodes inside the chest to swell - this can cause coughing or chest pain. Lymphoma cells may cause swelling of the liver or spleen, or enlargement of abdominal lymph nodes, causing pain. Lymphoma cells can sometimes spread to the bone marrow, causing pain in the bones. There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma (NHL).

HODGKIN LYMPHOMA

Hodgkin lymphoma is a type of lymphoma that is identified by the presence of a certain type of cell, called the Reed-Sternberg cell, that can be seen under the microscope. Hodgkin lymphoma usually causes swelling of lymph nodes, most often in the neck and upper body, but swelling can also occur in other areas of the body. Hodgkin lymphoma can sometimes cause other symptoms, such as recurring fevers, drenching night sweats, weight loss, or itching. Hodgkin lymphoma is uncommon in very young children and is more common in teenagers.

About 4 out of every 10 children who have lymphoma will have Hodgkin lymphoma.

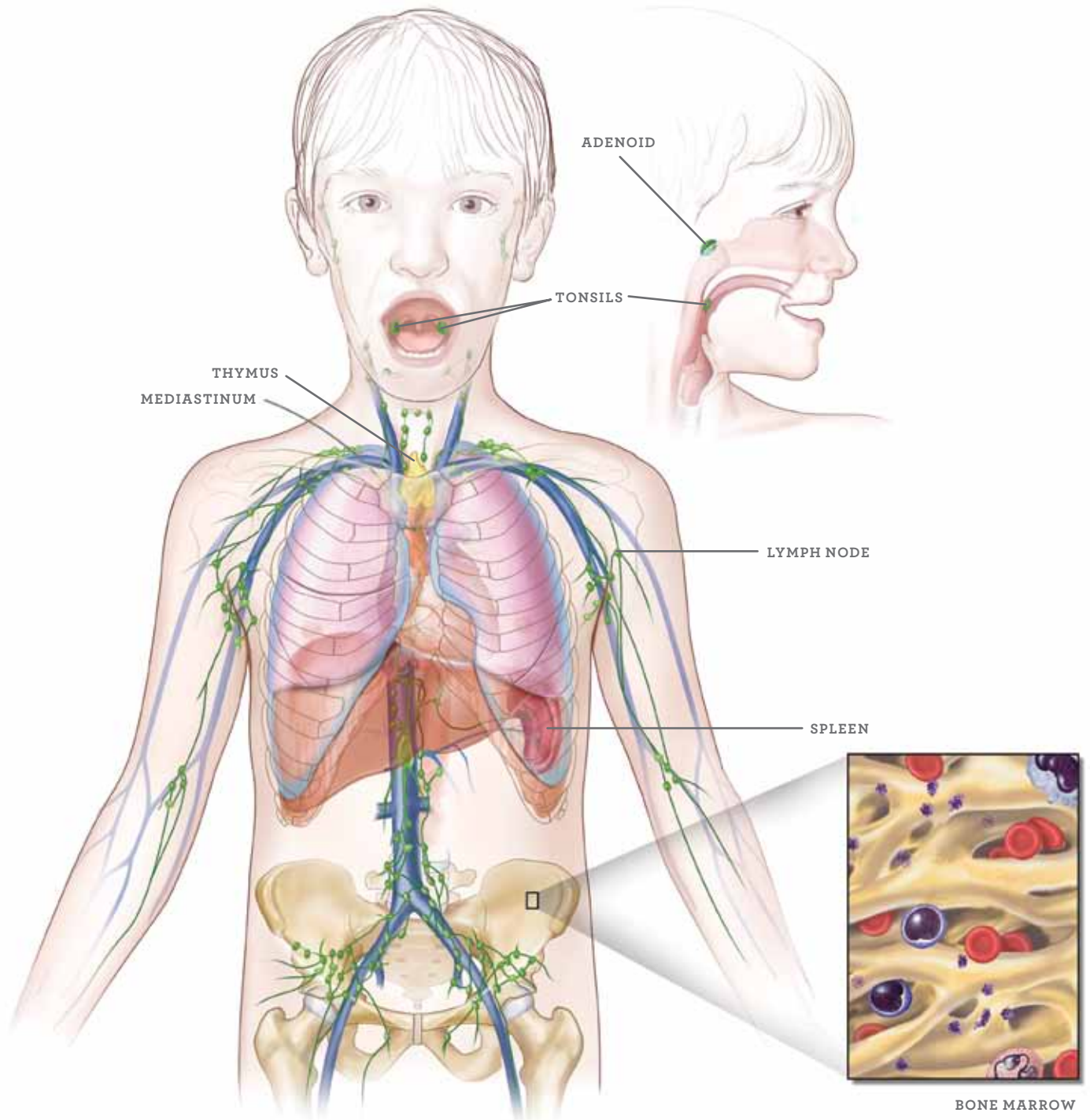
NON-HODGKIN LYMPHOMA (NHL)

Non-Hodgkin lymphoma (NHL) is a group of diseases arising from lymphatic tissues. The specific type of NHL depends on certain characteristics of the lymphoma cells, such as how they look under the microscope. Because lymphatic tissues can be found throughout the body, NHL can begin in almost any part of the body. NHL sometimes spreads to the spinal fluid (the fluid that surrounds the brain and spinal cord), and can be detected by looking at the spinal fluid through a microscope after doing a lumbar puncture (sometimes called spinal tap). Some types of NHL can cause skin rashes and bone pain. In boys, NHL can sometimes spread to the testicles, causing the testicles to become swollen.

There are more than a dozen types of NHL, but the following are the most common types seen in children and teenagers:

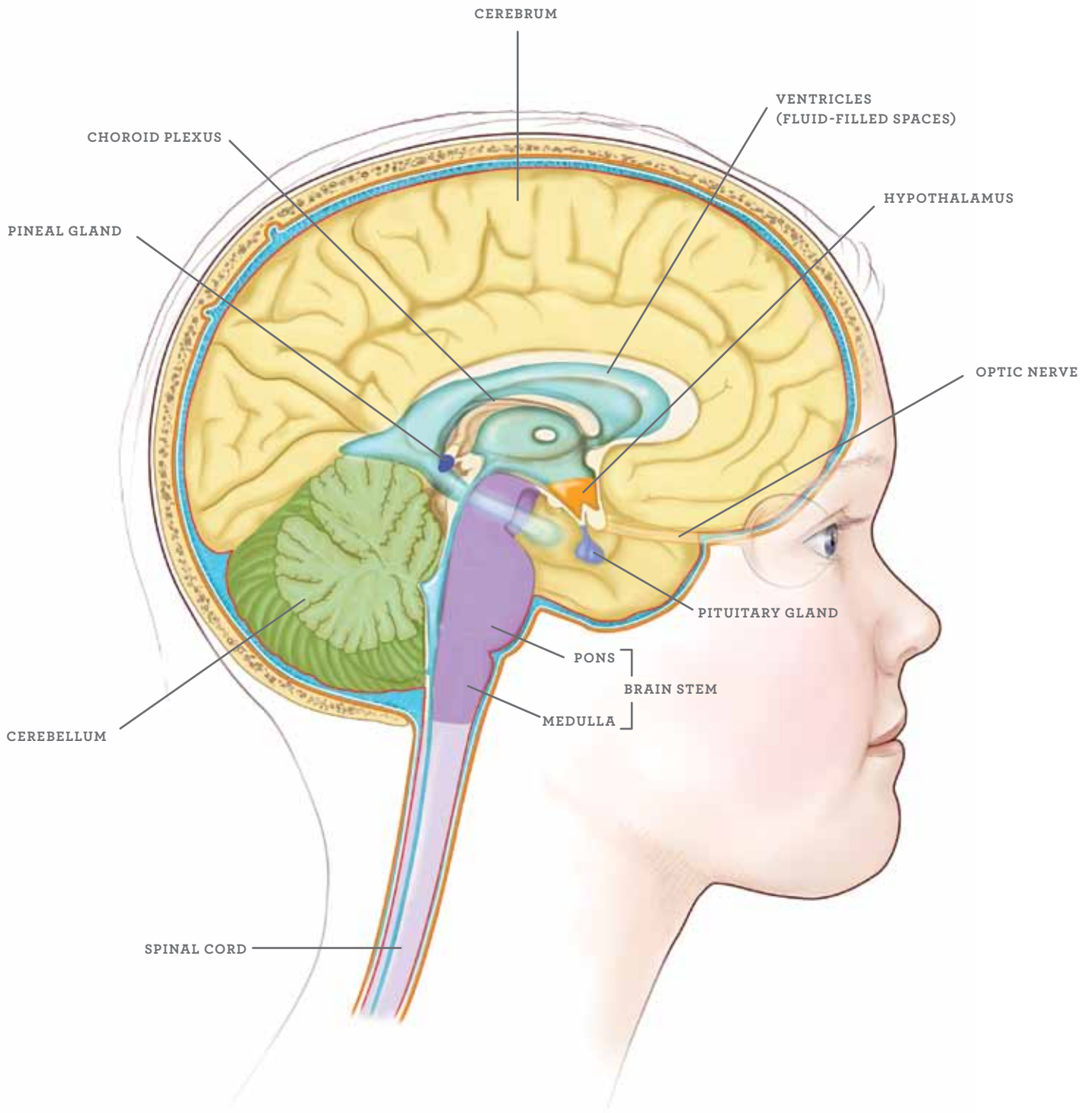
- Burkitt lymphoma
- Large B-cell lymphoma
- Lymphoblastic lymphoma
- Anaplastic large cell lymphoma

About 6 out of every 10 children who have lymphoma will have NHL.



LYMPHOID SYSTEM

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BRAIN + SPINAL CORD

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Solid Tumors

BRAIN AND SPINAL CORD TUMORS

ALSO KNOWN AS CENTRAL NERVOUS SYSTEM (CNS) TUMORS

The central nervous system (CNS) is made up of the brain and the spinal cord. Together, these important organs control body functions such as movement, thinking, learning, breathing, and heart rate. CNS tumors develop through a series of mutations or mistakes in a CNS cell that allows it to multiply uncontrollably. Clumps of these CNS cells form tumors. There are many different types of CNS tumors. Some CNS tumors are malignant (fast-growing and have a tendency to spread) and others are benign (slow-growing and do not spread), but all types of CNS tumors can be serious. Types of CNS tumors occurring in childhood include:

- **Choroid plexus tumor** Choroid plexus tumors arise from the tissue that produces cerebrospinal fluid (the fluid that cushions the brain and spinal cord). These are rare tumors that tend to occur in infants and very young children.
- **Craniopharyngioma** Craniopharyngiomas are tumors that arise in the central part of the brain, near the pituitary gland. Craniopharyngiomas are usually slow-growing tumors that cause pressure on surrounding tissues and structures within the brain. They also commonly cause deficiencies of hormones, causing difficulties with growth, water balance, and other problems.
- **Glioma** A glioma is a tumor that arises from the supportive tissue of the CNS known as the glia. There are three types of glial cells: astrocytes, oligodendrocytes, and ependymal cells. Gliomas are named for the type of glial cells in which the tumor begins. Some types of gliomas seen in childhood include astrocytoma, ependymoma, glioblastoma, and oligodendroglioma. Gliomas are sometimes named for the area of the CNS where they arise, such as the optic nerve or brain stem. Gliomas may also be graded, a designation that indicates the rate at which the tumor is likely to grow. Slower growing gliomas are categorized as low grade (grades 1 and 2), and faster growing gliomas are categorized as high grade (grades 3 and 4).
 - **Astrocytoma** Astrocytomas are named for the star-like shape of the astrocyte cells that are seen in this tumor. Astrocytomas are the most common types of CNS tumors in children and can occur in any part of the brain or spinal cord.
 - **Ependymoma** An ependymoma is a CNS tumor that begins in the lining of the ventricular system of the brain or in the central area of the spinal cord. The ventricular system contains the cerebrospinal fluid that bathes and cushions the brain and spinal cord.
 - **Glioblastoma multiforme (GBM)** GBM is a fast-growing form of astrocytoma.

- **Oligodendroglioma** Oligodendrogliomas develop from cells that make myelin, a substance that covers and protects nerves. Oligodendrogliomas can be fast or slow growing, and most commonly arise in the cerebral (upper) brain hemispheres.
- **Medulloblastoma/PNET** Medulloblastomas arise from primitive (very immature) nerve cells within the CNS. Medulloblastoma is a tumor that occurs in the cerebellum (lower part of the brain that controls balance and other motor functions). A Primitive Neuroectodermal Tumor (PNET) is a tumor that looks like medulloblastoma under the microscope, but usually occurs in a location other than the cerebellum.

CNS tumors are the most common solid tumors in children. About 1 in 5 children with cancer will have a CNS tumor.

GERM CELL TUMORS

Germ cells are reproductive cells that develop into testicles in males and ovaries in females. Germ cell tumors most commonly occur in the reproductive organs (testicles or ovaries). However, these tumors can also occur in other places within the body, including:

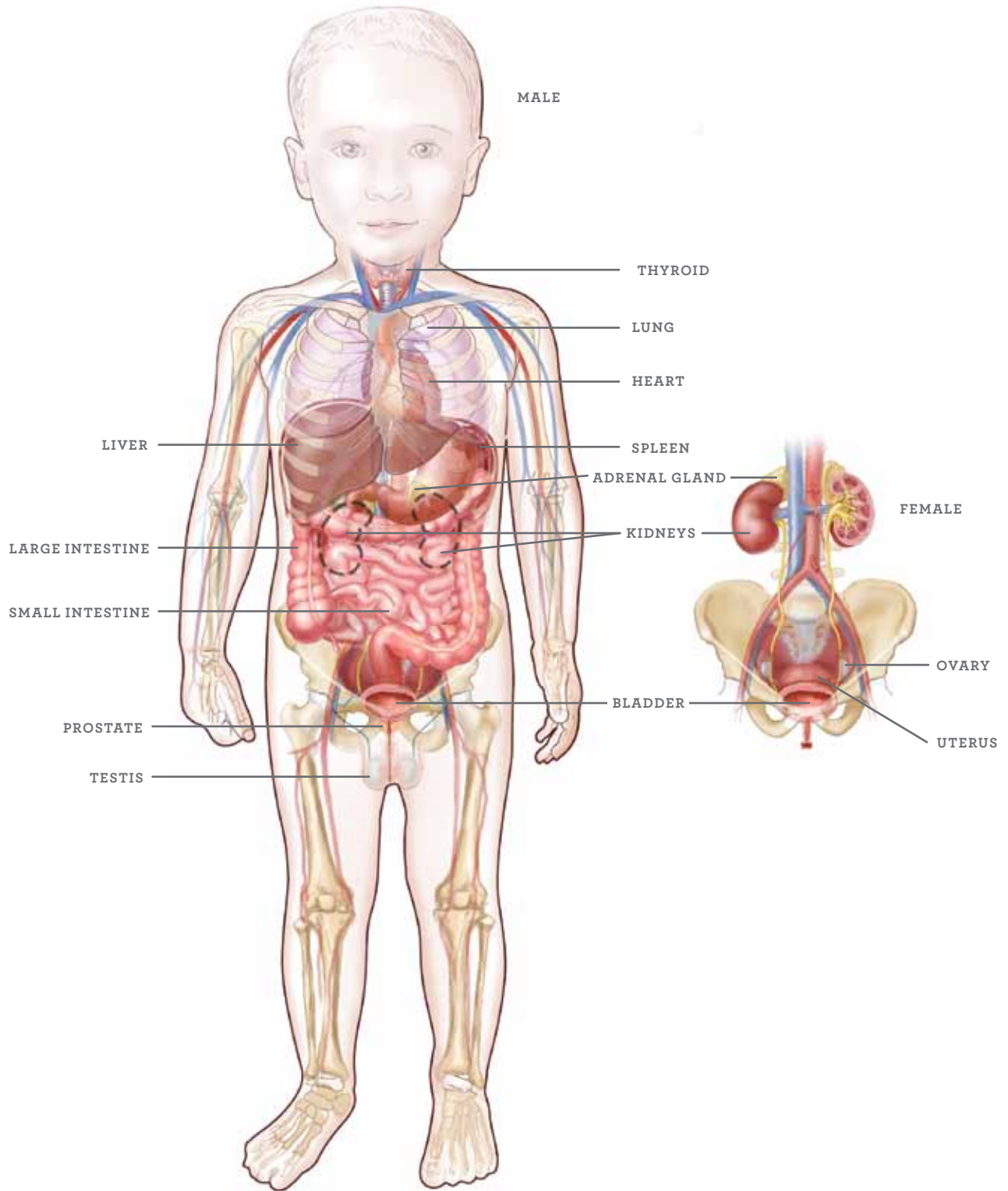
- Abdomen
- Pelvis
- Central chest area (mediastinum)
- Brain
- Lower back/tailbone area (sacroccygeal)

Germ cell tumors can be malignant (fast-growing and have a tendency to spread) or benign (slow-growing and do not spread).

Malignant germ cell tumors include several types, such as immature teratoma, yolk sac tumor, embryonal carcinoma, germinoma/dysgerminoma/seminoma, and choriocarcinoma. These tumors can damage the testicle or ovary and can spread to other parts of the body, such as the lung, liver, lymph nodes, and central nervous system. Some malignant germ cell tumors begin in the central nervous system, usually near the center of the brain.

Benign germ cell tumors include teratomas. A teratoma is a tumor that may contain several different types of tissue, such as hair, muscle, and bone. Although usually not as difficult to treat as malignant tumors, benign germ cell tumors can cause problems because of their size or location.

Germ cell tumors are rare. Only about 3 or 4 of every 100 children with cancer will have a germ cell tumor.



ORGANS + SKELETAL SYSTEM

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KIDNEY CANCERS

The kidneys filter waste out of the bloodstream, creating urine, which passes into the bladder. Kidney cancer arises when a mistake or mutation occurs during the formation of a young kidney cell. The change in the kidney cell causes the cell to grow out of control and become a cancerous tumor. The most common types of kidney cancer in childhood are:

- **Wilms tumor (nephroblastoma)** Wilms tumor is the most common type of kidney cancer in children. Usually, Wilms tumor occurs in one kidney (unilateral), but sometimes it can occur in both kidneys (bilateral). A Wilms tumor may grow without being detected until it becomes quite large. Wilms tumors can sometimes spread to other parts of the body, such as the lymph nodes in the abdomen, lung, and liver. Wilms tumor usually occurs in very young children.
- **Renal cell carcinoma** Renal cell carcinoma is a type of kidney cancer that begins when abnormal cells in the lining of very small tubes (tubules) in the kidney begin to grow out of control and form a growth, or tumor. Renal cell carcinoma can sometimes spread to other parts of the body, such as the lymph nodes in the abdomen, the lungs, and the brain. Renal cell carcinoma is an uncommon type of childhood cancer.
- **Clear cell sarcoma of the kidney (CCSK)** Clear cell sarcoma of the kidney (CCSK) is a cancerous tumor of the kidney that may spread to other areas of the body, such as the lymph nodes of the abdomen, lungs, brain, bone, and soft tissues. CCSK is an uncommon type of childhood cancer.
- **Rhabdoid tumor of the kidney (RTK)** Rhabdoid tumor of the kidney (RTK) is a cancerous tumor of the kidney that may spread to other parts of the body, such as the lymph nodes of the abdomen, lungs, brain, bone, and soft tissues. RTK is a rare type of childhood cancer.

About 6 out of every 100 children with cancer will have kidney cancer.

LIVER CANCERS

The liver is an organ located in the upper right side of the abdomen, under the rib cage. The liver is important in removing toxins from the blood, producing blood clotting proteins, and helping the body to digest food and use medicines. Liver cancers occur when a liver cell develops a series of mutations or mistakes that allows it to grow without the usual controls and to form cancerous tumors. The two most common types of liver cancers in children are:

- **Hepatoblastoma**, which occurs most frequently in infants or very young children. This is the most common kind of liver cancer in children.

- **Hepatocellular carcinoma (HCC)**, which occurs most frequently in older children and teens.

Only about 1 or 2 out of every 100 children with cancer will have liver cancer.

MELANOMA

Melanoma is a cancer of the skin. Melanoma begins with a series of mistakes or mutations in the melanocytes, the cells that give color to the skin, hair and eyes. The change in the melanocytes allows these cells to become cancerous and grow out of control. Although most melanomas occur in the skin, they can also occur in the eye.

Melanoma is not the most common type of skin cancer, but it is the most serious one. Fewer than 1 in 100 children with cancer will have melanoma.

NEUROBLASTOMA

Neuroblastoma is a type of solid tumor that occurs in the developing cells of the sympathetic nervous system. The sympathetic nervous system is a nerve network that carries messages throughout the body. Sympathetic nerves are responsible for actions of the body that are not under voluntary control, such as increasing heart rate, blushing, and dilating the pupils of the eye. Neuroblastoma begins when a change or mutation occurs in a young cell of the sympathetic nervous system, known as a neuroblast. The change allows neuroblasts to grow uncontrollably and form cancerous tumors. Neuroblastoma can begin anywhere in the body, but is most commonly found in the adrenal gland, located on top of the kidney. Other common locations for neuroblastoma include the neck, chest, abdomen, and pelvis, near the spine. Neuroblastoma can spread to other areas of the body, including the bone marrow, bones, and lymph nodes.

Neuroblastoma usually occurs in infants and young children. It is uncommon in older children and teenagers. About 7 out of every 100 children with cancer will have neuroblastoma.

RETINOBLASTOMA

Retinoblastoma is a solid tumor that occurs on the inside surface of the back of the eye, called the retina. The retina is a thin layer of nerve tissue that allows a person to see. Retinoblastoma begins when a change or mutation occurs in a young cell of the retina called a retinoblast. The change allows retinoblasts to grow uncontrollably and form a cancerous tumor. Retinoblastoma is usually seen in infants and children younger than 6 years of age. Retinoblastoma is an uncommon childhood cancer.

Only about 3 in 100 children with cancer will have retinoblastoma.

SOFT TISSUE AND BONE SARCOMAS

Sarcomas are solid tumors that are formed from young cells that normally become bone, muscle, and other soft tissues, such as ligaments and joints. Sarcomas begin when a change or mutation occurs in one of these young cells, allowing the cell to grow uncontrollably and form cancerous tumors. There are many types of sarcomas that occur during childhood.

About 12 in every 100 children with cancer will have a sarcoma.

- **Osteosarcoma** (sometimes called osteogenic sarcoma) is the most common cancer of the bone. Osteosarcoma starts when a change or mutation occurs in a young cell within the bone. The change allows the cell to grow uncontrollably and form cancerous tumors that can weaken the bone, cause pain, and spread to other parts of the body, such as the lungs. Osteosarcoma most often affects the bones of the arms and legs, particularly around the knee joint and in the upper arm near the shoulder, but can also occur in any bone in the body. Osteosarcoma most commonly affects teenagers and young adults, but it can occasionally occur in younger children.
- **Ewing sarcoma** is the second most common tumor of the bone. Other names for Ewing sarcoma are “Ewing sarcoma family tumor” and “peripheral primitive neuroectodermal tumor (pPNET).” It often affects the bones of the pelvis, chest, arms, and legs, but can occur in any bone in the body. Ewing sarcoma can also begin in the soft tissues instead of in the bone. Ewing sarcoma most often occurs in older children and teenagers.
- **Rhabdomyosarcoma** is a cancer that arises from cells that normally develop into muscle cells. Rhabdomyosarcoma begins when a change or mutation occurs in one of these young cells, called a rhabdomyoblast, allowing the cell to grow uncontrollably and form a cancerous tumor. Rhabdomyosarcoma may arise virtually anywhere in the body, but some of the most common sites for this tumor are:
 - Around the eye (orbital)
 - In the face near the lower part of the skull (parameningeal)
 - In the face or neck, but far from the lower part of the skull (non-parameningeal)
 - Arms and legs (extremities)
 - Urinary system and reproductive organs such as the bladder, prostate, paratestis (near the testicle) and vagina (genitourinary)

In children, there are two major subtypes of rhabdomyosarcoma:

- **Embryonal rhabdomyosarcoma** is the most common type and is usually seen in younger children. Embryonal rhabdomyosarcoma often occurs in hollow organs that have mucosal lining, such as the nasal passages and bladder. Botryoid and spindle cell rhabdomyosarcoma are subtypes of embryonal rhabdomyosarcoma.
- **Alveolar rhabdomyosarcoma** is more commonly seen in adolescents and often occurs in the arms and legs.

Almost two-thirds of children with rhabdomyosarcoma are under the age of 10.

- **Non-rhabdomyosarcoma soft tissue sarcomas (NRSTS)** are cancers that arise from young cells that normally develop into supporting structures of the body such as tendons, joint linings, and nerve coverings (often called soft tissues). In children, the most common types are synovial sarcoma, malignant peripheral nerve sheath tumor (MPNST), and undifferentiated sarcoma. However, there are at least 30 other types. NRSTS usually develop in the arms or legs, but can arise anywhere in the body. In childhood, they are most common in adolescents. Depending on the particular type, NRSTS can spread to lymph nodes, lungs, bone, skin, and brain.
- **Desmoplastic small round cell tumor** is a rare type of soft tissue sarcoma that is treated differently than other non-rhabdomyosarcoma soft tissue sarcomas (NRSTS). It usually occurs in the abdomen and can spread to the lymph nodes and the lining of the abdomen. It can also spread to the lungs, liver and bones. This cancer usually affects teenagers and young adults.
- **Desmoid tumors** are often called “desmoid fibromatosis” or “aggressive fibromatosis.” They usually occur in the arms and legs, but can start anywhere in the body. These tumors do not spread to other parts of the body but can arise in several different places (multifocal) at the same time.

CARCINOMAS

Carcinomas are cancers that begin in the epithelial tissues (tissues that cover the external surfaces of the body or that form the lining of glands or internal body cavities). Carcinomas are uncommon during childhood.

- **Adrenocortical carcinoma** is a cancer of the adrenal gland. The adrenal glands are located on top of the kidneys. The outer layer of the adrenal gland is called the adrenal cortex. The adrenal cortex makes hormones that help to balance salt and water in the body, control blood pressure, and contribute to masculine or feminine characteristics. Adrenocortical carcinoma develops in the adrenal cortex and can make high levels of hormones. The hormones can cause high blood pressure

and advanced or abnormal development of breasts, pubic hair, and other sexual characteristics. Adrenocortical carcinoma can sometimes spread to the liver and lungs. Adrenocortical carcinoma is rare in childhood.

Fewer than 1 in 100 children with cancer will have adrenocortical carcinoma.

- **Choriocarcinoma** (See Germ Cell Tumors, page 20)
- **Embryonal carcinoma** (See Germ Cell Tumors, page 20)
- **Hepatocellular carcinoma** (See Liver Cancers, page 22)
- **Nasopharyngeal carcinoma.** The nasopharynx is located in the upper part of the throat (pharynx) behind the nose. Nasopharyngeal carcinoma is a type of cancer that begins when abnormal cells in the nasopharynx begin to grow out of control and form a growth, or tumor. In children, nasopharyngeal carcinoma often spreads to the lymph nodes in the neck, causing them to be larger than normal. It can also spread to the lungs and bones. Nasopharyngeal carcinoma is rare in childhood. Fewer than 1 in 100 children with cancer will have nasopharyngeal carcinoma.
- **Renal Cell Carcinoma** (See Kidney Cancers, page 22)

THYROID CANCER

The thyroid gland is a butterfly-shaped organ that sits below the “Adam’s apple” in the front of the neck. The thyroid gland makes hormones that regulate temperature, energy level, weight, and appetite. Thyroid cancer begins when a change or mutation in a cell within the thyroid gland causes the cell to multiply uncontrollably and form lumps of cancerous cells called tumors. A cancerous thyroid tumor is called thyroid carcinoma. There are four types of thyroid cancer:

- Papillary (most common type, usually slow growing)
- Follicular (less common, usually slow growing)
- Medullary (tends to spread to other parts of the body)
- Anaplastic (fastest growing)

Thyroid cancer is rare in children, and is more likely to occur in older children and teenagers than in younger children. Only about 1 in every 100 children who have cancer will have thyroid cancer.

How is Cancer Diagnosed?

Many procedures or tests can be done to see if cancer cells are present in the body. Depending on your child’s symptoms and type of cancer, your child may have one or several of these tests.

For more information about the tests commonly used to diagnose cancer, see the “Tests and Procedures” section of this Handbook.

Cancer Staging for Lymphomas and Solid Tumors

Once the diagnosis is made, cancer staging is done for children with lymphomas and solid tumors. Staging is the way that the doctor finds out where the cancer is in the body. To determine the stage of your child’s cancer, the health care provider will order a number of tests. Once the stage of the cancer is known, you and your child’s health care team can talk about the best treatment plan.

The site where the cancer started is called the primary tumor. Cancer cells may spread to tissue around the primary tumor (local invasion) or break away and spread to other parts of the body (metastasis). Sites where the cancer has spread are called metastatic tumors.

Systems for staging cancer are different for different types of cancer. As a general rule, stage I is the least advanced (meaning that the cancer has not spread beyond the area where it started) and stage IV is the most advanced (meaning that the cancer has spread to distant parts of the body). Treatment is often different for different stages of disease. Therefore, your child’s doctor may need to know the stage of your child’s cancer before treatment recommendations can be made.

Causes of Childhood Cancer

Many parents wonder what caused their child’s cancer. A very small number of childhood cancers are caused by hereditary factors. This means that the child was born with a change in their DNA (the material inside every cell that tells the cell how to behave) that can cause some cells to develop into a cancer. Sometimes, this change in the DNA occurs in the early stages of development (before the child was born). Other times, this change of DNA is inherited from one of the child’s parents. When this happens, the parent may also have had the same type or a similar type of cancer. Childhood cancers that can be hereditary include retinoblastoma, malignant peripheral nerve sheath tumor, and adrenocortical carcinoma. Most other cancers are not hereditary.

Many parents fear that something they did or did not do caused their child’s cancer to develop. As far as we know, nothing that you or your child did caused or could have prevented the cancer. We know that cancer is not contagious. You cannot catch cancer from another person.

Scientists are working to find the causes of cancer in children. For now, we do not know the exact cause of most childhood cancers. Most parents think about what may have caused cancer in their child. Parents may feel responsible and blame themselves even though they could not have prevented the cancer. These feelings may be upsetting, but they are normal. If you have thoughts or concerns about what may have caused your child’s cancer, talk to your health care team.

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FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG
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Notes and Questions for Your Health Care Team

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Tests and Procedures

Throughout treatment, your child will have tests and procedures to help the health care team diagnose and care for your child. Some of these tests will be quick and easy for your child, and some may produce anxiety and/or pain. Because each child's experience is different, it is important to talk with your health care team about the best way to support your child.

Medicines to Help Decrease Pain During Tests and Procedures

There are many ways and different types of medicines to help decrease your child's pain and anxiety during tests and procedures. Members of the health care team can help prepare you and your child for the test and help your child find positive ways to cope with the test.

Below is information on the different types of medicines available to help your child through their tests and procedures.

LOCAL ANESTHESIA (NUMBING THE SKIN AND TISSUES)

Before a test or procedure is done, a numbing medicine can be used. This medicine may be in the form of a topical cream, patch, spray or other device placed on the skin. The medicine numbs the skin and tissues underneath the skin. For many children this is enough numbing medicine for a needle procedure. When necessary, after the medicine has numbed the surface of the skin, another numbing medicine can also be given using a small needle that is placed a little bit deeper into the tissue. This numbing medicine may burn a little bit at first, but after one to two minutes, the tissue will feel numb all the way down to the bone.

SEDATION

If more than local anesthesia (numbing the skin and tissues) is needed, your health care team will talk with you about sedation (using medicine, or a combination of medicines, to help your child relax or sleep through the test or procedure.) Sedation can be delivered at different levels, ranging from a feeling of calm, to sleepiness, to general anesthesia (completely asleep). The level of sedation will depend on your child's condition, procedure anxiety, and hospital guidelines. Whatever the level of sedation your child needs, the goal is the same: to keep your child comfortable and free from pain. Talk with your health care team to learn more about what type of sedation is best for your child and what sedation guidelines are followed by your hospital.

The tests that your child will have depend on the type of cancer or illness they have, what phase of treatment they are in, their age, and on the policies of your hospital. This list includes many common tests, but your child may have tests that are not on this list.

Procedures

BIOPSY

In a biopsy, a small piece of tissue is taken out of the body and tested for cancer cells.

An **open biopsy** is when the skin is opened during surgery to get a sample of tissue.

A **closed biopsy** is when a needle is put into the tissue without cutting open the skin.

Some biopsies are done in the operating room under general anesthesia (completely asleep). Other biopsies are done using local anesthesia (numbing the skin and tissues). The type of anesthesia used will depend on where the tumor is in the body and the condition of your child.

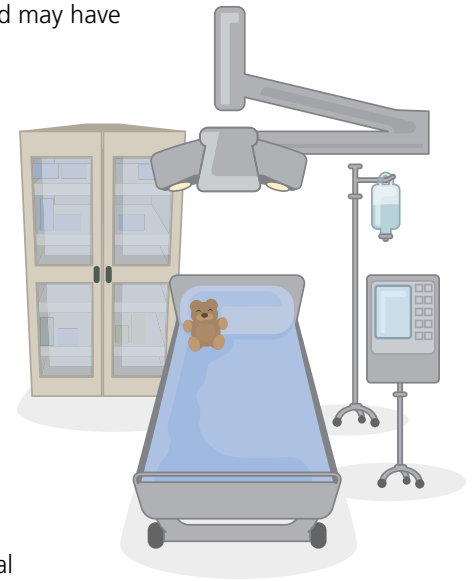
BONE MARROW ASPIRATE

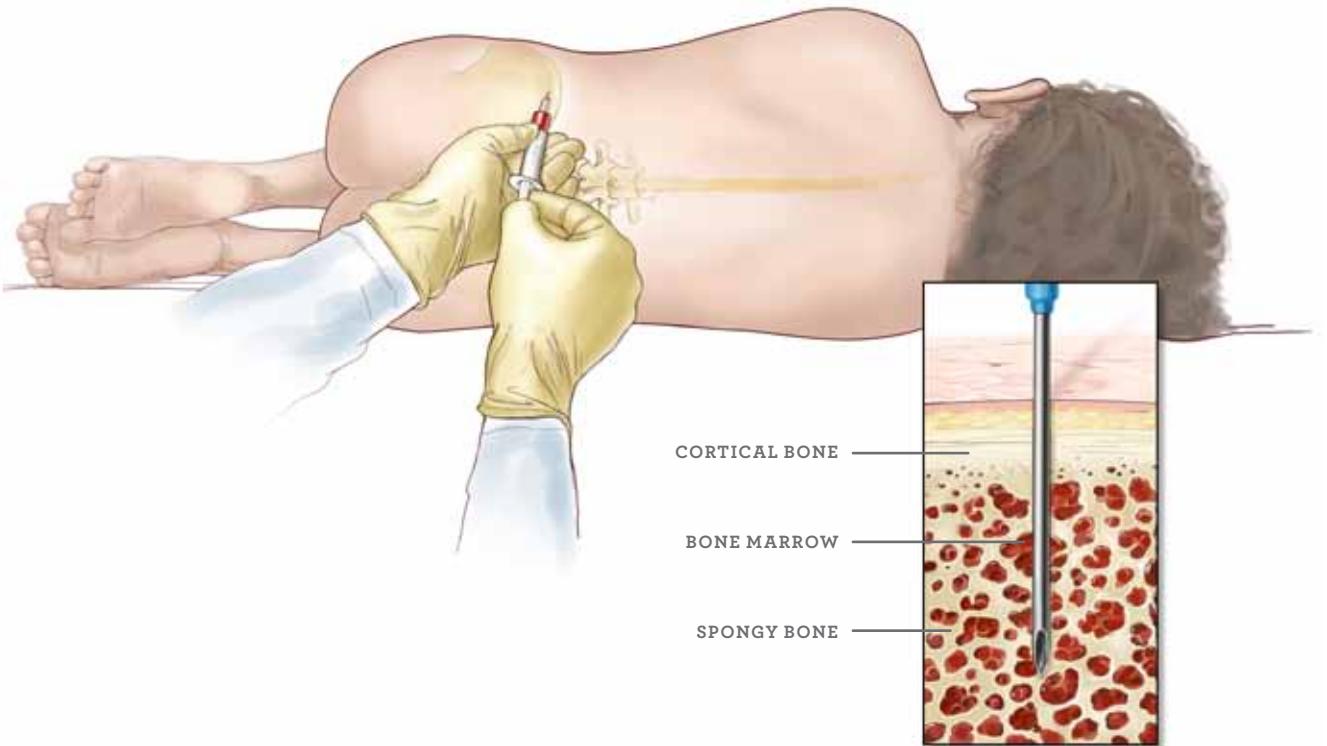
A bone marrow aspirate is a test that is done to see if cells in the bone marrow are healthy and to find out if cancer cells have spread to the bone marrow from another part of the body. Bone marrow is the factory where blood cells are made. Bone marrow is found in the center of bones and is made up of both spongy bone and liquid marrow.

For this test, a needle is placed in a bone (usually the hipbone) and a small sample of liquid bone marrow is pulled into a syringe. The marrow is sent to the laboratory to be tested for cancer cells.

This test may be painful. There are many ways to help decrease pain. Talk with your health care provider about the way your hospital manages pain with bone marrow aspirates.

There is a small chance that your child could bleed under the skin or get an infection where the needle was placed.





BONE MARROW ASPIRATE

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BONE MARROW BIOPSY

While a bone marrow aspirate is done to look at the blood cells in the bone marrow, a bone marrow biopsy is done to study an actual piece of spongy bone marrow. Bone marrow biopsies also help determine if the bone marrow cells are healthy and if there are cancer cells present. For this test, a needle is placed in a bone (usually the hipbone), and a small piece of the spongy bone marrow is removed and sent to the laboratory for testing.

This test may be painful. There are many ways to help decrease pain. Talk with your health care provider about the way your hospital manages pain with bone marrow biopsies.

There is a small chance that your child may bleed under the skin or get an infection where the needle was placed.

LUMBAR PUNCTURE

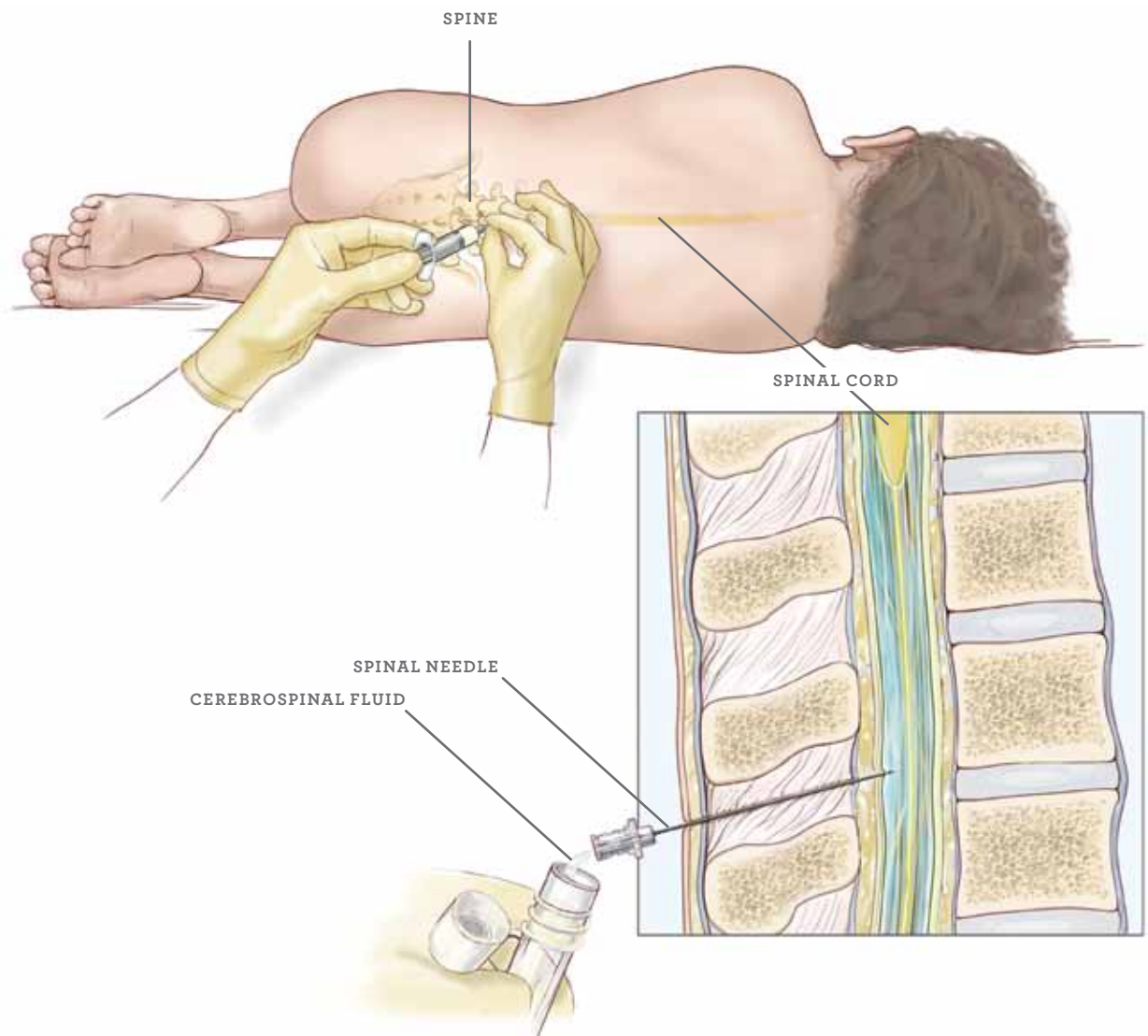
A lumbar puncture (also called a spinal tap) is a test that is done to see if there are cancer cells in the fluid that cushions the brain and spinal cord. This fluid is called cerebrospinal fluid or CSF. Your child will be asked to lie on their side with the chin tucked to the chest and knees pulled up. In some cases children can sit up and curl the back by tucking the chin to the chest. When the back is in a curved position, a needle can be placed in between the bones of the spine (vertebrae). Fluid from the spinal canal can then be removed through the needle and dripped into a tube that is sent to the laboratory to be tested. For some types of cancer, chemotherapy may be given into the spinal canal through the same needle after the fluid is removed for testing.

This test may be painful. There are many ways to help decrease pain. Talk with your health care provider about the way your hospital manages pain with lumbar punctures. Some children may have a headache or backache after the test. After the test there is a small chance that your child may get an infection or bleed under the skin.

X-Rays and Scans

BONE SCAN

A bone scan takes pictures of the bones to see if any tumor activity is present. This is done by injecting a small amount of radioactive isotope, or tracer, into a vein. The tracer contains about the same amount of radiation as an x-ray. The tracer travels to bones where there is tumor activity. The scanner can then detect any areas in the bones that are not normal. Your child will need to lie still while in the scanner. Some children may need sedation to be able to lie still for the whole scan.



LUMBAR PUNCTURE

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COMPUTERIZED AXIAL TOMOGRAPHY SCAN (CT OR CAT SCAN)

A CT scan uses a special x-ray to make a detailed picture of the inside of the body. The scan is done in the radiology department. Contrast dye may be given in a vein and/or by mouth before the test. Contrast dye helps distinguish normal structures from cancer. Some children need sedation to be able to lie still for the whole scan.

MAGNETIC RESONANCE IMAGING (MRI)

An MRI uses a special machine (scanner) to look inside the body. The scanner uses magnetic waves to create a picture of the inside of the body. Your child will need to lie still on the table inside the MRI machine while the pictures are made.

Your child should not wear anything metal (jewelry, belt, etc.) because the machine attracts metal. Your child will hear and feel a rhythmic knocking sound, like a drumbeat, when the machine is scanning.

You may not be able to stay in the same room with your child during this test; however, you and the staff can always hear and see your child. The length of the test depends on the part of the body being scanned. Some children need sedation to lie still for the whole test.

MIBG SCAN (META-IODOBENZYLGUANIDINE SCAN)

MIBG scans help locate and diagnose certain types of tumors in the body.

Neuroblastoma is one example of a tumor commonly diagnosed with a MIBG scan. The scan is done by injecting a small amount of radioactive tracer into a vein. After the tracer is given, pictures are taken under a scanner (similar to a CT scan). The scans may be scheduled 24, 48, and 72 hours after the tracer is given. Before and after the scan, a special medicine is given to protect the thyroid gland from the radioactive substance in the tracer. Be sure to ask your health care team about instructions to prepare your child for the MIBG Scan.

PET SCAN (POSITRON EMISSION TOMOGRAPHY SCAN)

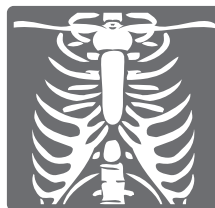
PET scans look for tumor activity in the body. They can also show infections or inflammation. A PET scan is done by injecting a small amount of radioactive isotope, or tracer, into a vein. The tracer travels to places in the body where there is tumor activity. After the tracer is injected, your child will have to lie very still on the PET scanner table while pictures are being taken. Be sure to ask about what instructions are needed to prepare for the PET Scan. For instance, there are special dietary instructions to follow, and there may be additional instructions if your child needs sedation.

ULTRASOUND

An ultrasound makes pictures of the inside of the body by bouncing sound waves off tissue or organs inside the body. Clear jelly is placed over the part of the body that is being studied. A small round probe (transducer) is then placed on the jelly and moved around to get a clear picture of the tissue or organ.

X-RAY

An x-ray is a picture taken of the inside of part of the body. For example, x-rays can show if a bone is broken or if there is an infection or fluid in the lungs.



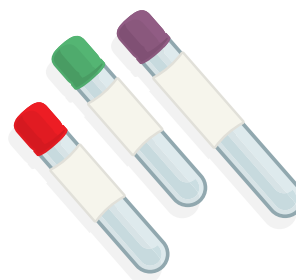
Blood and Urine Tests

BLOOD CHEMISTRIES (BASIC OR COMPREHENSIVE METABOLIC PANEL)

These tests help the health care team see how your child's organs (liver, kidneys) are handling the cancer treatment. The tests also show if the levels of sodium, potassium, and many other elements in the blood are normal.

BLOOD CULTURES

If your child has signs of an infection, the blood may be tested to see if bacteria, viruses, or fungi are present. This helps the health care team know how best to treat the infection.



COMPLETE BLOOD COUNT (CBC)

A CBC counts the different kinds of blood cells: white cells, red cells and platelets. A CBC is done for many reasons. One reason is to see how treatment is affecting the bone marrow, where blood cells are made. Other reasons are to see if your child needs a transfusion or is at increased risk for infection. A CBC is often ordered with a differential count. A differential count (or "diff") refers to the distribution of the various types of white cells in the blood. The values are expressed in percentages.

CREATININE CLEARANCE

A creatinine clearance test is a way to measure how well the kidneys are working. Creatinine is a protein that is in blood and urine. The amounts of creatinine in the blood and in the urine are used together to measure kidney function. You will collect your child's urine in a container for 12 to 24 hours. You will need to collect the urine every time your child goes to the bathroom. The amount of urine collected needs to be accurate. Your child's blood will also be tested for the level of creatinine in the blood.

GLOMERULAR FILTRATION RATE (GFR)

The glomerular filtration rate test looks at how well the kidneys are working. A special substance, known as a tracer, is given in a vein. After the tracer is given, follow-up tests are done to determine how quickly the tracer passes through the kidneys and is removed from the body.

PHARMACOGENETIC BLOOD TESTS

Pharmacogenetic blood tests help identify variations in genes (the material in cells that is inherited) that may be useful in guiding dosing of certain medicines. Certain genes may be partly responsible for how medicines are processed by the body.

PHARMACOKINETIC/PHARMACODYNAMIC BLOOD TESTS

These blood tests are sometimes done as part of a clinical trial (research study). They help us learn how your child's body handles medicine and what happens to the medicine once it is taken. By performing these blood tests, we hope to learn how to better use these medicines in children with cancer.

TUMOR MARKER BLOOD TESTS

Tumor markers may be found in tumor tissue or released from a tumor into the bloodstream or other body fluids. In some childhood cancers, blood and/or body fluids can be tested for specific tumor markers to help determine if cancer is present and monitor response to treatment.

URINALYSIS (UA)

A urinalysis tests the urine to see if it contains things that should not be there. A small amount of urine is collected in a cup and sent to the laboratory to be tested. The number of white blood cells and red blood cells in the urine will be counted. The urine will also be tested for protein, bacteria, and sugar.

Hearing Tests

AUDIOGRAM

An audiogram measures hearing by testing how well a child can hear sounds of different pitches and different degrees of loudness. Your child may wear headphones and/or go into a soundproof booth for this testing.



BRAINSTEM AUDITORY EVOKED RESPONSE (BAER)/ AUDITORY BRAINSTEM RESPONSE (ABR)

Some children are not able to have an audiogram, including very young children and those who cannot understand the test instructions. These children can have their hearing tested by measuring brain waves. This is called Brainstem Auditory Evoked Response (BAER) testing, also known as Auditory Brainstem Response (ABR). Small electrodes will be taped to your child's head, and their brainwave responses to various sounds will be recorded. Your child will usually be given medicine so that they sleep during this test.

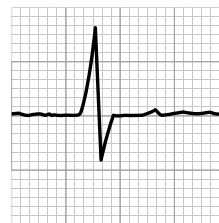
Heart and Lung Tests

ECHOCARDIOGRAM (ECHO)

An echocardiogram is a test of the strength and function of the heart. This test is done using an ultrasound machine. A clear jelly is placed on the child's chest. The technician will move a small round probe (transducer) around on the chest. This probe sends sound waves to the heart, and the returning sound waves create a picture of the heart.

ELECTROCARDIOGRAM (EKG)

An electrocardiogram measures the rhythm of the heart. Small stickers, called leads, are placed on the chest and sometimes on the arms and legs. The leads are attached to a monitor that measures the heart rhythm. When the rhythm needs to be measured over several hours or a day, the test equipment is called a Holter monitor. The Holter monitor is placed in a pouch that the child can wear.



PULMONARY FUNCTION TESTS (PFTS)

Pulmonary function tests measure how well the lungs are working. The test measures how much air the lungs can hold and how well your child can push air out of the lungs. Your child will be asked to blow into a plastic mouthpiece connected to a machine. The machine measures the amount of air breathed in and the force of the air breathed in and out. Your child will probably be asked to repeat the test a few times to get an accurate reading.

For more information about tests and procedures at your hospital, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG

Notes and Questions for Your Health Care Team

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Clinical Trials

Clinical trials are research studies done to help us understand more about diseases, such as why they happen and how to best treat them. The tremendous progress that has taken place in developing successful treatments for children with cancer has been made possible through clinical trials.

Children's Oncology Group (COG)

The Children's Oncology Group is the largest pediatric clinical trials group in the world and has treated more children with cancer than any other organization. Over 200 hospitals participate in the COG. For each new clinical trial, a group of doctors, nurses, and other experts plan how the treatment will be given. Members of the COG meet regularly to learn from past trials, review current trials, and plan new trials.

Types of Clinical Trials

There are two main types of clinical trials:

THERAPEUTIC TRIALS

Therapeutic trials are research studies done to determine the safety and effectiveness of a treatment for a particular disease. New clinical trials are planned based on the results of past trials, taking the best known therapy and asking what might make it better. Every trial is reviewed by many experts who come from both inside of the COG and from outside agencies like the National Cancer Institute, Hospital Review Boards, and a Data Safety Monitoring Board. The knowledge gained from clinical trials has improved treatment for children with cancer by increasing survival rates and reducing side effects and long-term effects of therapy. Most children with cancer are treated on a clinical trial.

NON-THERAPEUTIC TRIALS

These trials help us learn more about childhood cancer by studying the:

- Biology and behavior of cancer cells
- Side effects of cancer treatments and how to reduce them
- Causes of childhood cancer and the number of children affected per year
- Quality of life during and after cancer treatment
- Genetic make-up of a person and how that can affect the chance of getting cancer and the response to cancer treatment

Phases of Therapeutic Clinical Trials

Therapeutic clinical trials are done in phases. Each phase of a clinical trial builds on the previous phases, with the overall goal of developing better treatments.

PHASE I

PURPOSE	<ul style="list-style-type: none"> · To find the safest dose of a new treatment or the highest dose with the least side effects · To learn how the body responds to a new treatment
METHOD	<ul style="list-style-type: none"> · Patients are given a low dose of the treatment to see if side effects occur. The doses are increased in groups of patients until unwanted side effects are observed.
PATIENTS	<ul style="list-style-type: none"> · Phase I trials are only offered to patients whose disease has not responded to other less experimental treatments.
POTENTIAL BENEFITS	<ul style="list-style-type: none"> · Individual patients usually do not benefit from this type of clinical trial. · A very small number of patients may respond to the new treatment. · Future children benefit from what is learned in this type of trial.
POTENTIAL RISKS	<ul style="list-style-type: none"> · Side effects of the new treatment may not be known. · Patients may feel discomfort or pain from the new treatment. · Patients may spend more time in the hospital or clinic to receive the new treatment or have tests done to evaluate the response.

PHASE II

<p>PURPOSE</p>	<ul style="list-style-type: none"> · To learn if a new treatment works in patients with specific types of cancer · To learn more about how a new treatment may affect the body
<p>METHOD</p>	<ul style="list-style-type: none"> · Patients with specific types of cancer receive a new treatment using a dose that was found to be safe in a Phase I trial. · Patients are followed for side effects and to see whether the cancer shrinks or goes away.
<p>PATIENTS</p>	<ul style="list-style-type: none"> · Phase II trials are offered to patients whose disease has not responded to other less experimental treatments or to patients whose disease doesn't have a standard treatment.
<p>POTENTIAL BENEFITS</p>	<ul style="list-style-type: none"> · A small number of patients may have a response from the new treatment. Future children benefit from what is learned from this type of trial.
<p>POTENTIAL RISKS</p>	<ul style="list-style-type: none"> · Benefits of the treatment are not known. · Patients may feel pain or discomfort from side effects. · Patients may spend more time in the hospital or clinic to receive the new treatment or have tests done to evaluate the response.

PHASE III

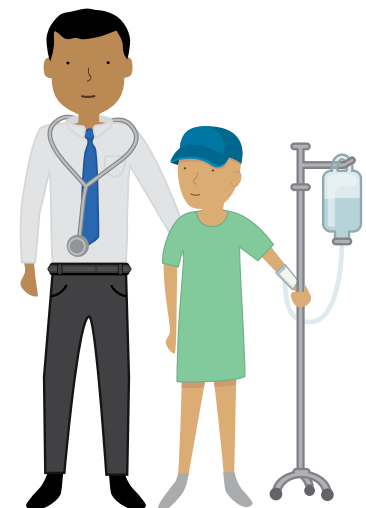
PURPOSE	<ul style="list-style-type: none"> To learn if a new treatment that is known to be effective in treating a specific type of cancer is better in some way than standard treatment for the disease (for example, better cure rates, longer control of disease, fewer or less serious side effects, or fewer days in the hospital)
METHOD	<ul style="list-style-type: none"> Patients may be assigned to the standard group or a new group by a method called randomization.
PATIENTS	<ul style="list-style-type: none"> Patients with the same type of cancer who are eligible for standard treatment.
POTENTIAL BENEFITS	<ul style="list-style-type: none"> Phase III trials may identify new treatments that are better than the benefits of standard therapy.
POTENTIAL RISKS	<ul style="list-style-type: none"> The new treatment is thought to be at least as good as the standard treatment. It is not known if the new treatment will be better than the standard treatment.

PILOT STUDIES

In addition to the Phase I, II and III studies described above, you may also hear about pilot studies. Pilot studies are small scale studies done to see if a new treatment or research method will be useful in a larger scale Phase I, II or III study.

Facts About Clinical Trials

The findings from clinical trials add to knowledge and progress in the treatment of cancer. Since childhood cancer is rare, by trying different treatments and looking at the results we can find out which treatments are the best much more quickly. By treating children on clinical trials at COG-affiliated hospitals, overall survival rates have improved from less than 10% in the 1950's to over 80% at the present time. Organized clinical trials have made the difference.



Benefits and Risks of Clinical Trials

You may ask yourself, “How does my child benefit from being on a clinical trial?”

SOME BENEFITS OF CLINICAL TRIALS ARE:

- Treatment that is up-to-date and that researchers believe may have better results
- Children with cancer in the future may be helped by what is learned from clinical trials today, just as your child benefits from what has been learned from children who participated in past clinical trials
- Careful oversight of treatment from the local oncology team and multiple other experts that are a part of the COG research network

SOME RISKS OF CLINICAL TRIALS ARE:

- The new treatments may have different or more serious side effects than those known with the best current treatment
- Participants in randomized trials and their health care providers will not be able to choose the treatment the child receives
- Your child may spend more time at the clinic or hospital getting treatment or tests
- The new treatment may not work for your child’s disease

Does My Child Have to be on a Clinical Trial?

The choice is up to you. You may choose not to enter your child on a clinical trial. You may also choose to remove your child from a trial at any time. Your choice will not affect your child’s ability to receive care at your hospital.

If you decide not to enroll in a clinical trial, your child will receive what is known as the current standard treatment. Standard treatment is the current best known therapy.

To help you make a decision, you may want to get a second opinion. A doctor who is not a part of your current health care team will review your child’s history, test results, and exam. The doctor will give you their opinion about your child’s treatment plan. Some insurance companies require a second opinion before starting treatment. Your child’s doctor may refer you to another expert doctor. In the United States, the National Cancer Institute has a toll-free number (1-800-4CANCER) and a web site (www.cancer.gov) to help you find cancer centers and doctors all over the country.

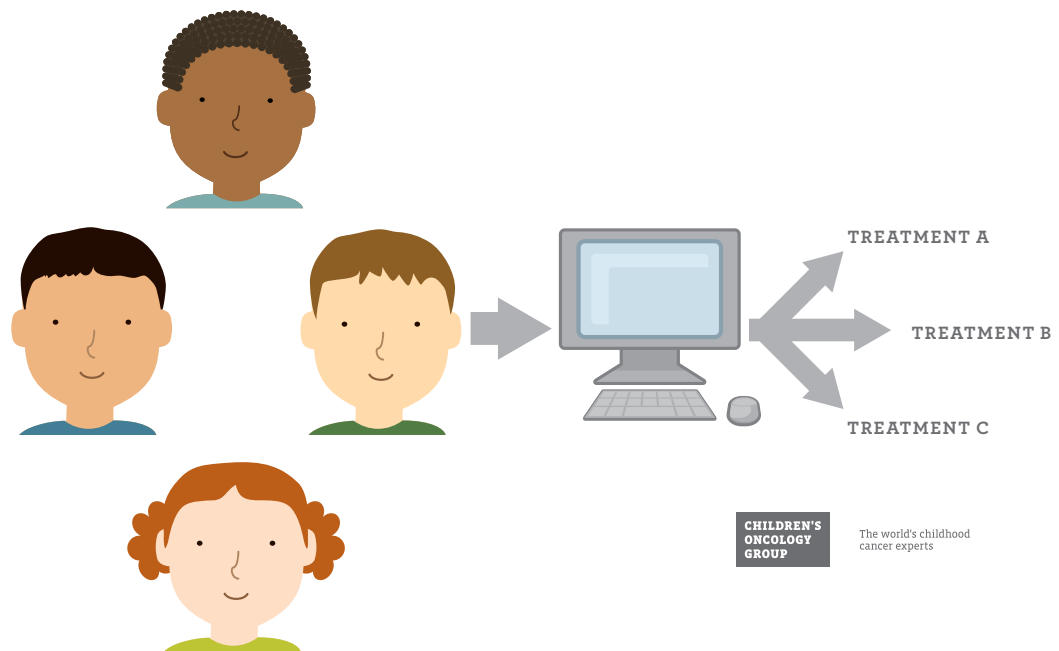
How are Clinical Trials Reviewed?

After a review by experts in the Children's Oncology Group (COG), a trial is sent to the National Cancer Institute (NCI) for approval. Once approved by the NCI, the trial is sent to an Institutional Review Board (IRB). An IRB is a committee that includes health professionals and people from the community who were not involved in designing the clinical trial. The IRB reviews a clinical trial to make sure that the rights of people who are in clinical trials are protected. Each trial is reviewed many times by different experts within and outside of COG before being started at a treatment center.

Randomization

Your child may be in a clinical trial that compares two or more treatment plans. Usually one treatment plan is the standard or current best known treatment. The other plan or plans have slight changes or additions that may improve survival rates, control disease longer, cause fewer or less serious side effects, and/or decrease days spent in the hospital. To learn if one treatment is better, each child is assigned randomly to one of the treatment plans by a computer. Randomization is a process like flipping a coin that assures each child has a fair and equal chance of being assigned to any of the treatment plans. Participants in randomized clinical trials, and their health care team, cannot choose which treatment they receive.

In most clinical trials, we do not know which treatment plan is better until all of the children on the trial have completed treatment and have been followed for several years. However, if one of the treatment plans is found to be better or safer than the others while the trial is in progress, enrollment on the trial is suspended and all children currently in the trial are given the treatment with the best results, if possible. If a clinical trial is not currently open when your child is diagnosed, your child will receive the standard treatment.





Informed Consent

A member of your child’s health care team will explain the treatment plan in the clinical trial to you. You will have opportunities to review the information and ask questions. Once your questions have been answered you will be asked if you give your permission for your child to participate in the clinical trial. This is called giving parental permission or informed consent. You will be asked to sign a form that describes the clinical trial including the treatment plan. This form lists the risks and benefits of the treatment plan and provides you with a list of the side effects of the medicines and any additional therapy. When you sign the form, you are saying that you understand what the health care team has explained to you and you agree to start treatment on the clinical trial.

If your child is old enough to understand, they will be asked if they give their permission to participate in the clinical trial. When a minor child (usually a child younger than 18 years old) gives permission, the child is giving assent. Members of your health care team will help explain the clinical trial to your child in words that they can understand. If your child is legally considered an adult, they will need to give consent and sign the form themselves.

Informed consent is a process that does not stop after you sign the consent form or start treatment. Every day in the hospital or at each clinic visit, your health care team will talk with you about the plan of care. This is your chance to ask questions and decide whether or not you agree with the plan. If you decide to have your child participate in a clinical trial and later change your mind, you may remove your child from the clinical trial at any time. Your health care team will continue to provide the best care possible for your child.

Treatment Plan

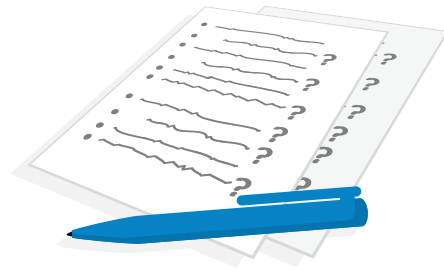
A member of your health care team will review the treatment plan in the clinical trial for your child. A schedule for each treatment, test, and procedure is listed on a therapy delivery map (sometimes called a road map), which is an overview of your child’s plan of care. You can look at the therapy delivery map to see when the next treatment is scheduled. You can also see what tests are planned. You and/or a member of your health care team may create a calendar that contains the information from your child’s therapy delivery map.

Keep in mind that each child is different, and the treatment schedule may change. These changes will depend on how your child responds to treatment. Delays in treatment are common when a child gets a fever or has low blood counts. For more information, please see 'Effects of Cancer Treatment on the Bone Marrow,' starting on page 60.

What Questions Should I Ask?

Before meeting with your health care team, write down any questions that you have. You may feel so overwhelmed that you can't think of any questions. Below are some examples of questions you may want to ask. (These questions can also be found in the *Hope and Help Journal* available through CureSearch. Ask your health care team if they have journals available.) Asking these questions, and any other questions you may have, is encouraged throughout all phases of treatment.

- What is the name of the cancer my child has?
- What caused my child's cancer?
- What are the best available treatment options for my child?
- What is the likelihood the treatment will be successful?
- How will you be able to tell if the treatment is working?
- Will my child need to stay in the hospital for treatment?
- How long will the treatment last?
- Who can help me explain the diagnosis and treatment to my child (and my other children)?
- Will my child be able to attend school during treatment?
- Are there any activities that are off limits to my child during treatment?



Bring your *Hope and Help Journal* or a pen and paper to your meeting to take notes. You may want to ask a friend or relative to come with you to take notes for you. You can also ask the health care provider if you can audio-record the meeting.

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Notes and Questions for Your Health Care Team

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Treatment and Effects

How Is Cancer Treated?

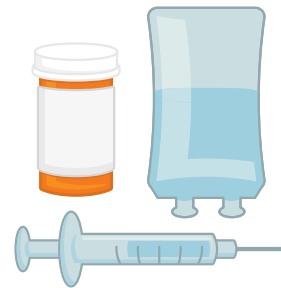
Each type of childhood cancer may be treated differently, depending on what researchers have found to be the most effective treatment for the particular type of cancer. The most common types of cancer treatment are described in the following section. Your child may receive one or a combination of the following treatments at different time points in their therapy.

CHEMOTHERAPY

Chemotherapy is medicine that treats cancer by stopping cells from growing or by destroying cells. Several types of chemotherapy medicines may be used because they each stop cell growth or destroy cells in a different way. When chemotherapy destroys cancer cells, healthy cells may also be damaged. Damage to healthy cells can cause side effects. Often the side effects get better or go away once the chemotherapy treatment is over. See pages 60-71 for information about side effects of chemotherapy.

Chemotherapy can be given by:

- Mouth
- Into a vein
- Into the muscle
- Into the spinal fluid



Your child's chemotherapy may be given by one or more of these methods. How your child's chemotherapy will be given depends on the type of cancer being treated and the chemotherapy medicines that work best for that type of cancer.

The schedule for your child's chemotherapy will be explained to you by the health care team. Chemotherapy is often given in cycles. A cycle is a period of chemotherapy treatment followed by a period of rest. The rest period allows time for the body to build healthy new cells before the next treatment. For example, your child may receive chemotherapy for one week followed by two weeks of rest. These three weeks make up one cycle. You can get information about your child's chemotherapy schedule and each type of chemotherapy medicine that your child will be receiving from your child's health care team.

For information about the safe handling of chemotherapy, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

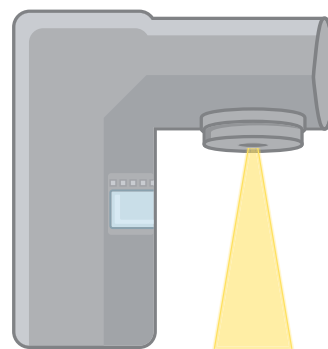
RADIATION THERAPY

Radiation therapy delivers high energy beams that damage DNA and destroy rapidly growing cells, such as cancer cells. Radiation may be given by itself or in combination with other therapies, such as chemotherapy and surgery. Radiation can damage both healthy cells and cancer cells, but the healthy cells are better at healing themselves. Unlike chemotherapy, radiation does not cause cell damage throughout the body. Radiation only damages cells in the area of the body where the radiation is given.

Radiation therapy can be delivered externally or internally. External beam radiation is the most common delivery method used for children with cancer. This method uses a machine to deliver high energy beams to a specific part of the body.

Examples of external beam radiation include:

- **Three-dimensional conformal radiation**—delivers shaped radiation beams from different directions that surround the cancer and avoid normal healthy tissues
- **Intensity modulated radiation therapy**—allows both the strength of the radiation beam and its shape to be precisely modulated so that it surrounds the cancer and minimizes exposure of the normal tissues
- **Proton beam radiation therapy**—is similar to three dimensional conformal radiation therapy, but uses a different form of radiation, known as a proton beam
- **Stereotactic radiosurgery**—delivers a large dose of radiation to the tumor in one session and is usually done under general anesthesia



Examples of internal beam radiation include:

- **Brachytherapy**—radioactive pellets placed in or near the tumor
- **Systemic radiation therapy**—a radioactive liquid delivered by mouth or intravenously

If your child needs radiation, you will meet with a Radiation Oncologist (an attending physician who specializes in the delivery of radiation therapy). They will explain which method of radiation delivery is best for your child, along with the risks and benefits.

A simulation session will be done before treatment starts. A simulation is when the radiation field (area to receive radiation) will be precisely determined. Sometimes marks are placed on your child's body and should not be washed off until after the radiation

treatments are finished. Usually tiny permanent ink dots (tattoos) are made to mark the area receiving radiation. Your child's radiation oncologist will explain the type of markings that will be used for your child.

Your child will need to lie still during the time that the radiation treatment is given. Many young children are able to do this successfully after receiving coaching and preparation from their treatment team. If your child is very young or unable to lie still, they may be given medicine (sedation or general anesthesia) so that they are asleep while the radiation treatment is being given.

Radiation can make the skin sensitive in the area of the body being treated. You can clean your child's skin with mild soap and water. Discuss with your radiation care provider which creams or powders should be used on your child's skin for protection from the radiation effects.

SURGERY

Different types of surgery are used to treat cancer. Sometimes, taking out the tumor may be the only treatment needed, but usually chemotherapy or radiation is also used to kill any remaining cancer cells. Most surgeries take place in the operating room while your child is asleep under general anesthesia.

Primary surgery

Primary surgery removes all or most of the tumor at the time of diagnosis. Sometimes, due to tumor size or its location in the body, the tumor cannot be safely removed right away. In this case, chemotherapy or radiation may be given before surgery to help shrink the tumor and make it easier to remove.

Second look surgery

Second look surgery is performed after treatment with chemotherapy and/or radiation. Surgeons are able to see how well the treatments have worked in killing the cancer cells, and may be able to remove any remaining tumor.

Supportive care surgery

Supportive care surgery is done to help your child through their cancer treatment. If treatment makes it difficult for your child to eat, a feeding tube may be placed into your child's stomach or digestive tract until they are able to take enough nutrition by mouth. Your child will most likely need to have a central venous line (catheter) placed. This line will make it easier to deliver intravenous (IV) fluid and medicine as well as draw blood.



CENTRAL VENOUS LINES (CVLS)

A central venous line is a semi-permanent catheter or access device. It provides a safe way to deliver cancer therapy and supportive care intravenously, by connecting with a large, central vein that leads to the heart.

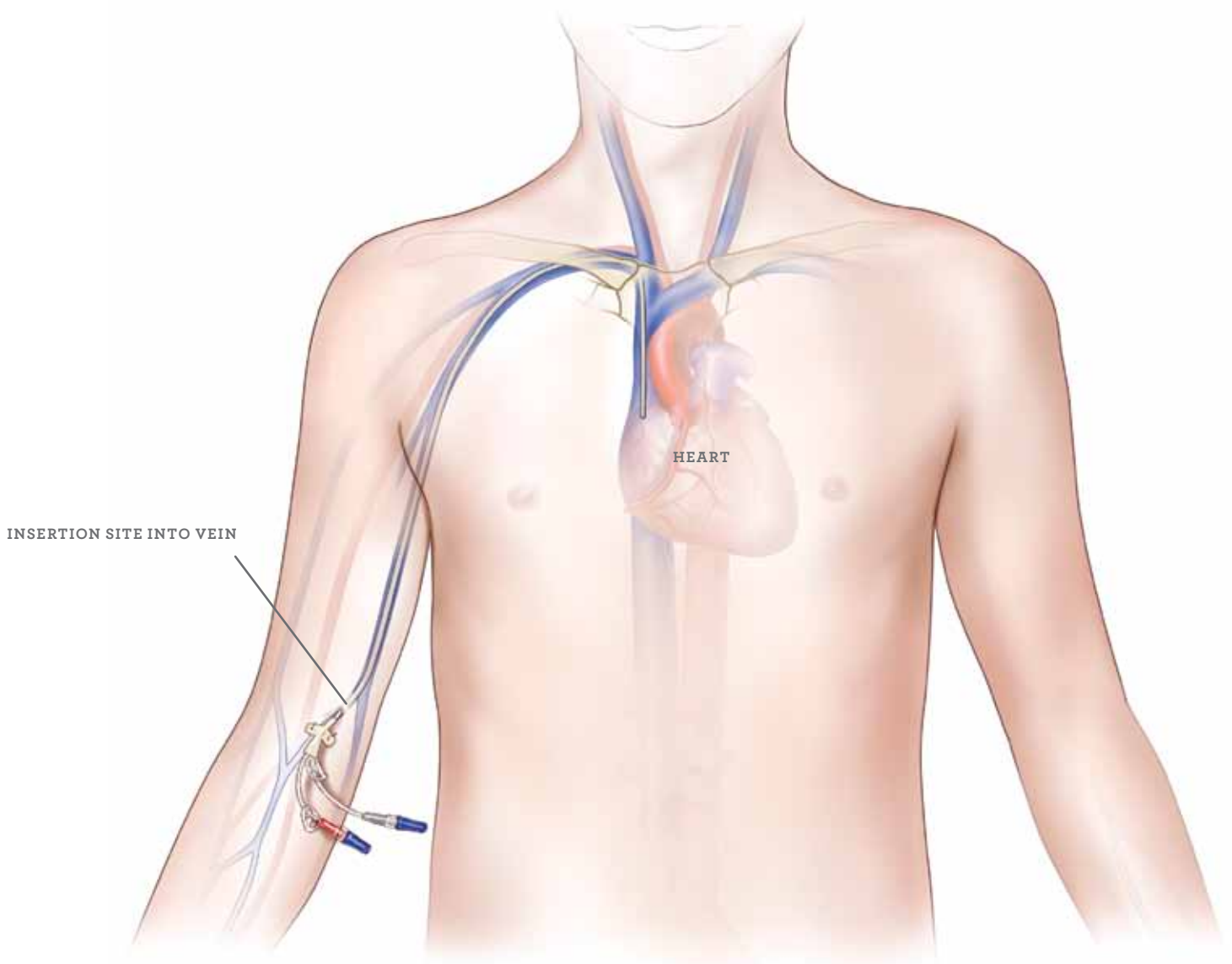
There are two types of central venous lines: external and internal.

- An **external line** can be on the chest or in the arm.
 - Types of external lines in which the catheter comes outside on the chest include a CVL, Broviac®, or Hickman®.
 - External central lines in the arm are called PICC lines (peripherally inserted central catheter). A PICC line is put in through a vein in the arm and then threaded up to a large vein that leads to the heart.

An external line can have one, two, or three access points to deliver many different therapies at the same time. This is especially helpful with complicated cancer therapy.

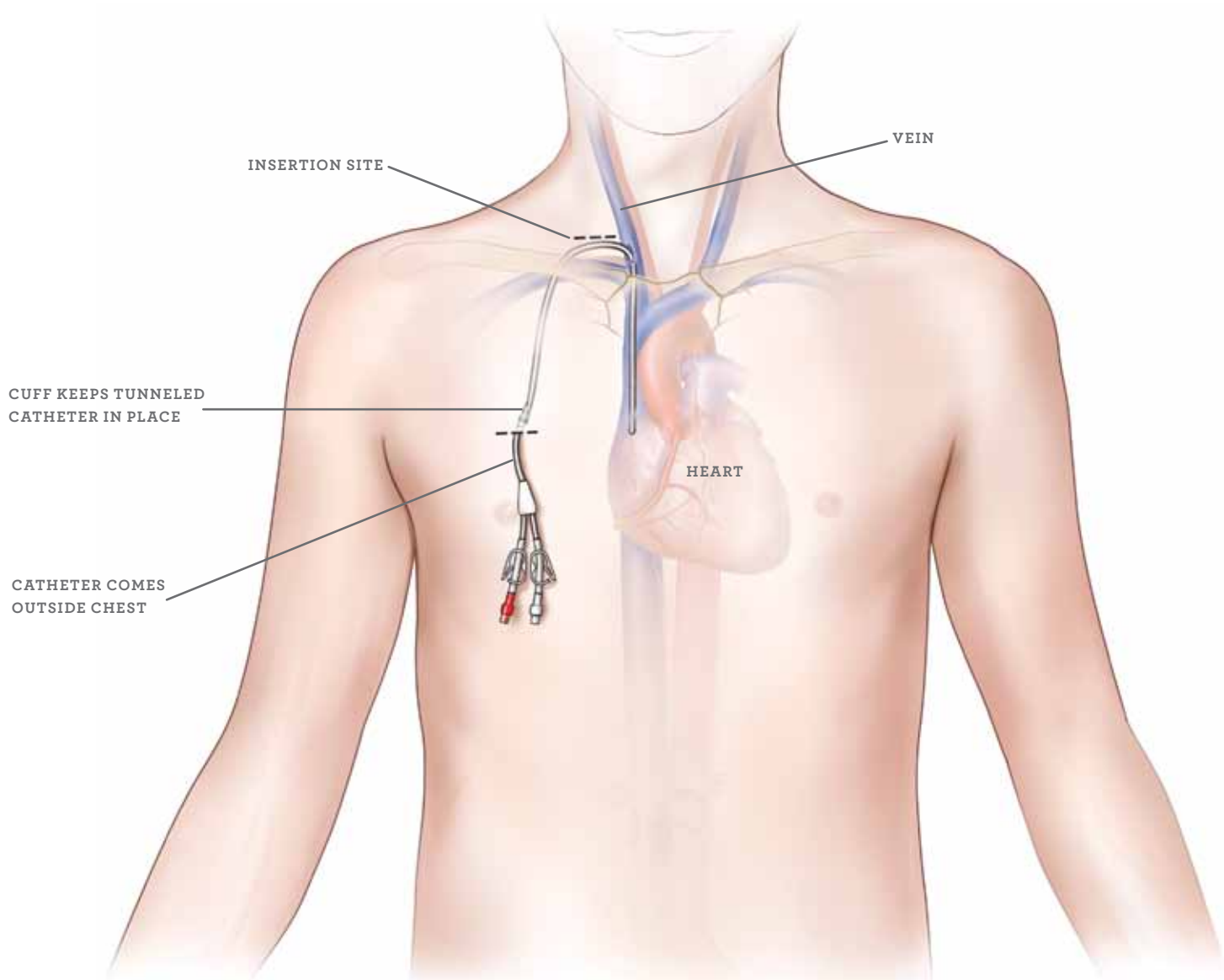
- An **internal line (sometimes called a port)** is one that stays under the skin. Examples of internal lines include a Medi-Port or PORT-A-CATH®. The port is a round, disc-like device that is usually placed in the chest. A special needle is used to access the port and deliver therapy. Medicine can be used to numb the skin over the port before the needle is inserted. A port can have one or two access points to deliver different therapies at the same time. When the port is not in use, the needle is removed and nothing remains on the outside of the skin.

See pages 90-91 for information about caring for central lines.



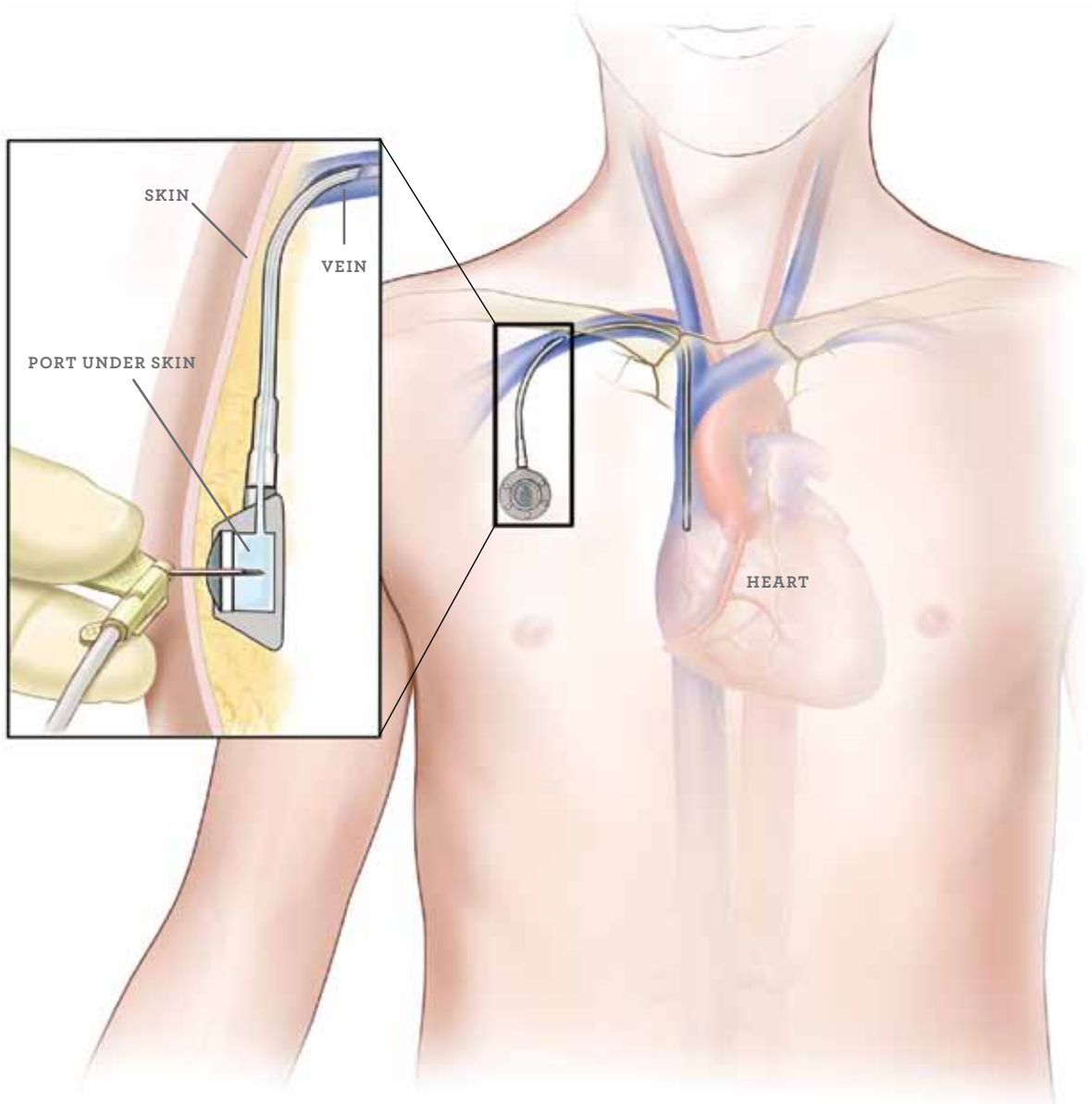
PICC

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EXTERNAL CVL-CHEST

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PORT

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HEMATOPOIETIC STEM CELL TRANSPLANT (HSCT)

The bone marrow is the factory where the blood cells are made. Bone marrow is found in the spongy part of bones, especially in the hips, spine, ribs, breastbone, and legs. The youngest type of blood cell is called a stem or progenitor cell. As a stem cell matures, it becomes a white cell, red cell, or platelet.

For some cancers, very high doses of chemotherapy and radiation are needed to get rid of all the cancer cells. These high doses of treatment may permanently destroy the normal stem cells in the bone marrow. The stem cells can be replaced with cells from a donor. This is called a **hematopoietic stem cell transplant**.

The stem cell donor may be the child with cancer, a relative, or someone not related to the child. If the child does not have cancer cells in the bone marrow, the child may be able to donate their own stem cells for a transplant. This type of transplant is called an **autologous transplant**. If the child's bone marrow has cancer cells, healthy stem cells are usually donated by a relative or someone not related to the child. This type of treatment is called an **allogeneic transplant**.

If your child needs a hematopoietic stem cell transplant, your health care provider will talk with you about the type of transplant that is best for your child. If your treatment center does not have a transplant program, you will be referred to a transplant center in your area.

BIOOTHERAPY

Biotherapy is sometimes called immunotherapy. Biotherapy uses the body's immune system to fight cancer cells. The immune system is a network of organs and cells that work to protect the body against disease. The immune system looks for cells that are not normal and tries to destroy them. Biotherapy can help the immune cells find cancer cells and destroy them.

Biotherapy can also help to lessen the side effects of cancer treatments by helping the body replace normal cells that have been damaged or destroyed. Biotherapy may also help prevent the spread of cancer cells in the body.

TARGETED THERAPIES

Targeted cancer therapies block the growth and spread of cancer, while limiting or avoiding damage to normal cells and tissues. Targeted therapies work by focusing on specific processes that play an important role in cancer cell growth. They target these processes so that cancer cells lose the ability to grow. An example of this would be stopping blood vessels that feed cancer cells, or interfering with signals that the cancer cells need for growth. Targeted therapies are a newer approach to cancer treatment.

PALLIATIVE CARE

No matter what type of treatment your child receives, supportive care will be available. One example of supportive care for children with cancer is palliative care.

Palliative care is a comprehensive and holistic approach to the care of children with serious illness. It supports children and families by easing physical symptoms as well as helping with the emotional, social, and spiritual aspects of living with a serious illness. It is important to know that palliative care can begin at any time during the course of the illness, and any child with a serious illness can benefit, whether a full recovery is expected or curative treatment is no longer an option. Many hospitals have palliative care teams who work along with the child's health care team to maximize the child's comfort and quality of life, as well as provide ongoing support to parents and family members. For more information about palliative care at your hospital, talk to your child's health care team.



What Are the Side Effects of Chemotherapy and Radiation Therapy?

Side effects occur when healthy cells are damaged. Different chemotherapy and radiation treatments cause different side effects. Side effects may happen right away, a week to ten days later, or even months to years later.

In general, the side effects from chemotherapy depend on the type and dose of chemotherapy. Side effects of radiation depend on which part of the body is treated with the radiation therapy. For example, if the hip receives radiation, only the skin, bone marrow, and hipbone in the area where the radiation was given may be affected. Your health care provider will talk with you about the side effects that your child may experience.

In this section, some of the most common side effects of cancer treatment are described. Things that you and your child can do to prevent, watch for, and treat the common side effects of cancer treatment are discussed.

Effects of Cancer Treatment on the Bone Marrow

The bone marrow is the spongy tissue inside the bones, especially in the hips, spine, ribs, breastbone, and legs. The bone marrow is the “factory” where blood cells are made. When some types of chemotherapy are given, or when radiation is given to the bones, the factory slows down and not as many blood cells are made. This may cause low levels of the three main types of blood cells:

- **White blood cells** fight infection
- **Red blood cells** carry oxygen to the body
- **Platelets** help stop bleeding

The blood counts are checked with a test called a **Complete Blood Count or CBC**. Children who receive cancer treatment commonly have low blood counts. The blood counts are often lowest one week to ten days after chemotherapy is given.

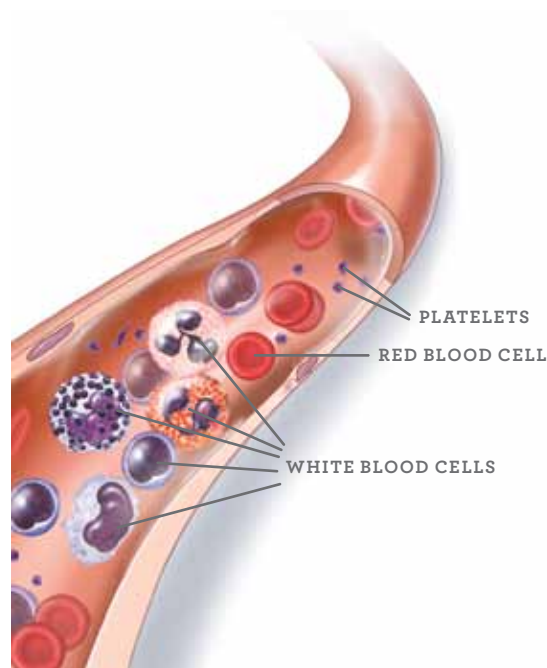
LOW WHITE BLOOD CELL COUNT (LEUKOPENIA)

White blood cells (WBCs) fight infection. When you have a low number of WBCs the risk of infection increases. In some cases, your child may be given a medicine, such as G-CSF, to help increase the number of white blood cells that are made in the bone marrow.

Differential

Different types of white blood cells have different jobs. The “differential” is part of the blood count report that shows the number of the different types of white blood cells in your child’s blood count.

- **Neutrophils** help to fight infections
- **Lymphocytes** make antibodies to fight infections
- **Monocytes** help to fight infection by killing and removing bacteria and other infectious organisms
- **Basophils** and **eosinophils** respond during an allergic reaction



BLOOD CELLS

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You will hear the term ANC, which stands for Absolute Neutrophil Count. The ANC is the total number of neutrophils in your child’s white blood cell count. We often refer to the ANC as the infection-fighting count. When the ANC is low, it is referred to as **neutropenia**. The lower the ANC drops, the higher the risk of infection. When the ANC drops below 500, the risk of infection is high. If your child becomes ill or has a fever when their ANC is low, there is a chance your child will need to be admitted to the hospital for antibiotics and care. There is also a chance that scheduled chemotherapy will be delayed until the ANC reaches a safe level. This chart shows the risk of infection according to the ANC:

ANC Value	Risk for Infection
Lower than 500	Highest
500 to 1000	Moderate
More than 1000	Lower

On most blood count reports, you will see the ANC already calculated for you. You can also ask your health care provider to tell you the ANC. If you would like to calculate the ANC yourself, you can use this formula:

$$\text{ANC} = (\% \text{ segs} + \% \text{ bands}) \times \text{WBC}$$

Look at your child's differential. Add the percentage of segs (sometimes called polys or PMNs) and bands together (combined, these make up the neutrophil count). Multiply the neutrophil count by the white blood cell count (WBC).

Example: WBC = 1,000 % segs = 20% % bands = 1%

$$\text{ANC} = (\% \text{ segs} + \% \text{ bands}) \times \text{WBC}$$

$$\text{ANC} = (20\% + 1\%) \times 1,000$$

$$\text{ANC} = (0.21 \times 1,000)$$

$$\text{ANC} = 210 \text{ (high risk for infection)}$$

SIGNS OF INFECTION

Call your health care provider right away if you notice any signs of infection, such as:

- Fever
- Chills
- Cough
- Trouble breathing
- Diarrhea
- Pain
- Red, irritated skin



If your child has a central venous line (central line or port), check for redness, swelling, pain, or pus at the site. A child with a low ANC may not have redness or pus, but could still have infection.

TAKING YOUR CHILD’S TEMPERATURE

You do not need to take your child’s temperature every day. Take the temperature if your child feels warm to touch or does not feel or look well. Take the temperature by mouth or under the arm. Do not take a rectal temperature as this could cause bleeding or infection. Make sure that you have a thermometer at home that works and that you know how to use it.

Often, your child’s temperature will be measured in Celsius units when you are at the hospital. Below is a table to help you convert temperature from Celsius to Fahrenheit.

Temperature Conversion Table

°C	°F	°C	°F	°C	°F	°C	°F	°C	°F
35.6	96.0	36.7	98.0	37.8	100.0	38.9	102.0	40.0	104.0
35.7	96.2	36.8	98.2	37.9	100.2	39.0	102.2	40.1	104.2
35.8	96.4	36.9	98.4	38.0	100.4	39.1	102.4	40.2	104.4
35.9	96.6	37.0	98.6	38.1	100.6	39.2	102.6	40.3	104.5
36.0	96.8	37.1	98.8	38.2	100.8	39.3	102.7	40.4	104.7
36.1	97.0	37.2	99.0	38.3	101.0	39.4	102.9	40.5	104.9
36.2	97.2	37.3	99.1	38.4	101.1	39.5	103.1	40.6	105.1
36.3	97.3	37.4	99.3	38.5	101.3	39.6	103.3	40.7	105.3
36.4	97.5	37.5	99.5	38.6	101.5	39.7	103.5	40.8	105.4
36.5	97.7	37.6	99.7	38.7	101.7	39.8	103.6	40.9	105.6
36.6	97.9	37.7	99.9	38.8	101.8	39.9	103.8	41.0	105.8

FEVER / ILLNESS

A fever may be a sign of a serious infection. If your child has a fever, **call your health care provider** right away. Children who receive cancer treatment are at high risk for getting a serious infection in the blood. If this happens and your child does not receive medical care right away, your child could get very sick and this could be life-threatening. Sometimes infection can occur without fever. Any time your child has chills or does not look well, even if there is no fever, call your health care provider right away. Do not wait for the clinic to open. Do not give your child aspirin (salicylate), acetaminophen (Tylenol®), or ibuprofen (Motrin®, Advil®, and PediaProfen™) unless you are told to do so by your health care team.



For more information about fever guidelines at your hospital, refer to the “Information from My Hospital” section of this handbook, or ask your health care team.

LOW RED BLOOD CELL COUNT (ANEMIA)

Red blood cells carry oxygen throughout the body. Oxygen enters the lungs with each breath and binds (attaches) to hemoglobin in the red blood cells. Hemoglobin carries the oxygen to all the organs and tissues in the body. Two laboratory tests are done to measure the number and function of red blood cells: hemoglobin and hematocrit.

- **Hemoglobin** is a protein in the red blood cells that carries oxygen
- **Hematocrit** is the percentage of blood made up of red blood cells

Signs of a Low Red Blood Cell Count

When the hemoglobin count is low, the body is not able to carry as much oxygen around the body.

A person with low hemoglobin may have the following symptoms:

- Tiredness
- Shortness of breath
- Headache
- Fast heart rate
- Pale skin and/or pale gums
- Dizziness

A blood transfusion may be given if your child's hemoglobin is too low.

Blood Transfusions

If your child needs a blood transfusion, the blood given will match your child's blood type. The blood will be given over several hours into a vein, either through a central line, or an I.V. in the arm. Your child will be checked during the transfusion for signs of a reaction.

Sometimes concern is voiced about the risk of getting HIV/AIDS or hepatitis from blood transfusions. The risk of getting HIV or hepatitis from a blood transfusion is extremely small. Each donor is tested for infectious markers in the blood, such as HIV, hepatitis, and others. Blood that tests positive for any disease is discarded. Directed donation (blood donated by a family member or friend) may also be available. Research studies have shown that directed donation does not increase the safety of the blood. However, blood donations are always welcome, and giving blood is a way that friends and family can feel like they are helping. For more information about directed donation, ask your health care provider.

For more information about blood transfusions at your hospital, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

LOW PLATELET COUNT (THROMBOCYTOPENIA)

Platelets stop bleeding in the body by forming clots. When the platelet count is low, your child may be at risk for bleeding.

Signs of a Low Platelet Count

If your child has a low platelet count, you may see any of the following signs:

- Bruising or petechiae (small, red, pinpoint spots on the skin)
- Bleeding from the nose, gums, or central line
- Black stools or vomit (may mean blood is in the stomach or bowel)

Nosebleed

If your child has bleeding from the nose, sit your child upright as you apply pressure to the soft part of the nose, just below the bridge. Pinch the area with your thumb and finger. Hold the pressure for 10 minutes. **If the bleeding does not stop, call your health care provider.**



How to Prevent Bleeding

If your child has a low platelet count, they should not play contact sports (for example, football, rugby). Use a soft toothbrush when brushing teeth to prevent bleeding of the gums. Do not give your child aspirin (salicylate) or ibuprofen (Motrin®, Advil®, and PediaProfen™) unless you are told to do so by your health care team. These medicines cause the platelets to not work well. Some over-the-counter medicines like cold and flu medicines contain aspirin or ibuprofen. Read the labels and check with your health care provider before giving your child any over-the-counter medicines. Do not give your child an enema or a suppository (medicine put into the rectum), and do not check a rectal temperature. Putting anything in the rectum can cause bleeding.

Platelet Transfusions

If your child's platelets are low, a platelet transfusion may be given.

For more information about low platelets, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

Effects of Cancer Treatment on the Digestive System

NAUSEA, VOMITING, AND DIARRHEA

Chemotherapy and radiation therapy can cause nausea, vomiting, and diarrhea. Any of these symptoms can place your child at risk for dehydration (loss of fluids in the body).

Nausea and Vomiting

Some chemotherapy medicines and radiation therapy to the head, neck or stomach can cause nausea and vomiting. These treatments can irritate the stomach lining or trigger the nausea and vomiting center in the brain. Sometimes just thinking about the hospital experience can also create nausea and vomiting. This is called anticipatory nausea and vomiting.

Medicines to help decrease nausea and vomiting are given before, during and after chemotherapy and radiation therapy. They can also be given in preparation for a visit to the hospital or clinic. The type and amount of anti-nausea medicine will be based on your child's treatment plan and reaction to the treatment. It is important to let your health care provider know if your child has nausea or vomiting at any time. Additional medicine or other types of anti-nausea treatment can be used.

Decreasing Nausea and Vomiting

Some ways to help decrease nausea and vomiting include:

- Eat small meals or snacks
- Eat foods that are easy to digest (such as crackers, rice, gelatin)
- Take sips of cool clear liquids
- Eat food in a room that is free from cooking or other odors
- Rinse mouth after vomiting

Diarrhea

If your child has diarrhea (frequent, liquid stools), tell your health care provider the color, amount, and number of times in a day that your child had diarrhea. Some ways to help decrease diarrhea include:

- Eat a soft, bland diet (such as bananas, rice, applesauce, and toast)
- Eat small amounts of food more often, instead of large meals
- Avoid spicy, fried or fatty foods
- Limit high-sugar foods (juices, candies)
- Discuss with your health care provider whether milk or milk products should be limited

Dehydration

Fever, vomiting, and diarrhea can cause dehydration, especially if your child cannot drink enough to replace the fluid that is lost. If your child has dry skin or mouth, does not have tears when crying, or has small, infrequent amounts of dark urine, then your child may be dehydrated. **Call your health care provider if your child has any of these signs of dehydration.**



INCREASING FLUID AND FOOD INTAKE AT HOME

If your child has vomiting or diarrhea:

- Encourage your child to drink small amounts of fluid frequently. You might try giving your child a teaspoon of soda or other fluid every few minutes while reading, watching a movie, or relaxing together
- Give your child foods that are easy to digest, such as crackers, rice, toast, or soup
- Offer your child cold foods that do not have strong odors

Your health care provider may also prescribe medicines to decrease nausea, vomiting and diarrhea.

CONSTIPATION

Constipation is when a child has hard stools (bowel movements) that occur less frequently than usual. Chemotherapy (such as vincristine) and other medicines (such as pain medicines) can cause constipation. Some ways to help decrease constipation include:

- Encourage your child to drink water several times each day
- Encourage physical activity, such as walking, to stimulate bowel function
- If your child is not able to drink a lot of fluid, try foods that are high in water (such as fruits) to help decrease constipation
- Give your child foods that are high in fiber (fruits, vegetables, and whole grains)
- When starting a high-fiber diet, do it slowly
- Your health care provider may give you a medicine to make the stools softer
- Do not use enemas or suppositories without talking with your health care provider

WEIGHT GAIN OR WEIGHT LOSS

Weight Gain from Steroids

Steroids (such as prednisone or dexamethasone) may cause your child to gain excess weight. Steroids can cause an increase in appetite and a build-up (retention) of fluid. Your child:

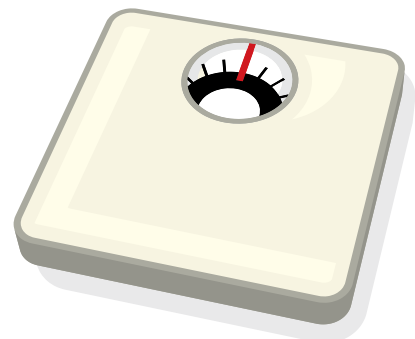
- May gain weight in the face and belly
- Will be hungry and need to eat often
- Should have healthy snacks several times a day
- Should have limited amounts of salty foods, because salt causes fluid retention
- Will usually lose weight after the steroids are stopped

Weight Loss

Many children lose weight during chemotherapy or radiation treatments. Your health care team will closely watch your child's weight. If your child cannot eat enough food to grow and stay healthy, your health care provider will talk with you about giving nutrition through a tube or I.V. Special nutrition can be given through a tube that goes through the nose into the stomach (nasogastric or N.G. tube) or a tube that is placed directly into the stomach through the wall of abdomen by surgery (gastrostomy or G-tube). If your child has vomiting and cannot take food into the stomach, a special formula can be given through an I.V. The formula is often called total parenteral nutrition (TPN).

Suggestions to help your child maintain or gain weight include:

- Stock up on healthy foods that your child likes
- Give small snacks or meals every 2 hours during the day
- Try to add extra calories to foods that your child likes, such as adding extra ice cream to a milkshake, spreading peanut butter on toast, or adding instant breakfast mixes to milk.
- Try not to offer a lot of fluids during meals, as this will make your child feel full more quickly
- Cook foods with strong flavors that may stimulate the appetite
- Let your child help cook food
- Encourage activity before meals to increase appetite
- Take advantage of the times that your child wants to eat
- Always have food that your child can get easily



For more information about nutrition, see page 90.

MOUTH CARE

Cells in the mouth can be affected by chemotherapy and radiation therapy to the head and neck. It is important to keep the mouth and teeth as clean as possible. Your child will feel more comfortable, and you can help prevent an infection from growing in the mouth.

Caring for Your Child's Mouth

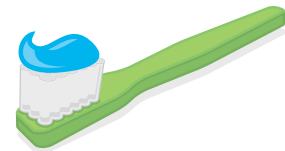
Have your child brush their teeth with a soft toothbrush after each meal and before bed. Rinse the mouth with water after brushing. Do not use mouthwashes that contain alcohol. Alcohol dries out the mouth. If a dry mouth is a problem, have your child suck on sugar-free hard candies or ask your health care provider about mouthwashes or other products for dry mouth.

Caring for Mouth Sores

Some chemotherapy medicines and radiation therapy to the head and neck can cause mouth sores (mucositis). The inside of the mouth may be red or may have sores that can be painful. You may also see white plaques (small raised areas) in the mouth that may be from a fungal infection.

If mouth sores are a problem:

- Give your child plenty of fluids
- Have your child drink fluids with a straw
- Avoid spicy or acidic foods
- Give your child foods that are cold or at room temperature
- Try soft, tender, or puréed (beaten or blended) foods
- Avoid dry or coarse foods
- Cut food into small pieces
- Rinse the mouth with water or a mouthwash recommended by your health care provider several times a day
- Avoid mouthwash that contains alcohol



Your health care provider may give your child a medicine to treat a fungal infection in the mouth (thrush). If the mouth sores are painful, your health care provider will give your child a pain medicine. **Call your health care provider if:**

- Your child cannot drink enough fluids
- Your child's medicine does not help take away the pain
- Your child cannot swallow comfortably



For more information about mouth care, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

Other Effects of Cancer Treatment

HAIR LOSS (ALOPECIA)

Some kinds of chemotherapy and radiation therapy to the head may cause hair loss or thinning of the hair. Hair loss may start 7 to 10 days after the treatment is given. In some cases all of the hair falls out, including eyelashes, eyebrows, underarm hair, pubic hair, etc. Some children and parents prefer to cut the hair as short as possible when the hair starts to fall out. Others prefer to shave the head to keep the hair from falling out slowly. Many children wear hats or scarves and some buy a wig to wear until the hair grows back. Your social worker or child life specialist can help you order a wig or hair accessory.

Hair will usually grow back when the cancer treatments become milder or end. Your child's hair may be a slightly different color or texture (curlier, thicker, or thinner) than before the cancer treatment. In some cases, especially with high doses of radiation, the hair may not grow back where the radiation was given.

FATIGUE

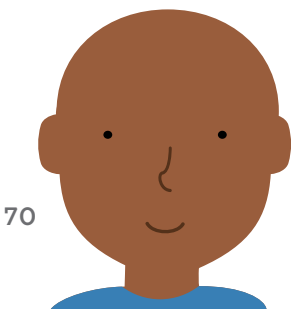
Many children with cancer have fatigue during and following treatment. Children may describe fatigue as being tired or feeling weak. Many things can cause fatigue:

- Cancer treatment (surgery, chemotherapy, or radiation)
- Low blood counts
- Poor nutrition
- Fever
- Pain
- Not getting enough sleep
- Poor quality of sleep
- Worry or depression
- Trying to do too much
- Lack of physical activity

Managing Fatigue

Tell your health care provider if your child has fatigue. You can do many things to help your child fight fatigue.

- When possible, encourage physical activity every day. If needed, a physical therapist can help with an exercise program to increase your child's strength and endurance.
- If your child's appetite is poor, offer healthy foods every two to three hours while awake.
- Try to make each snack as nutritious as possible. Talk to your dietitian for ideas.
- Avoid caffeine
- Have a regular bedtime routine
- Get plenty of sleep each night
- If your child is having pain that interferes with sleep, discuss this with your health care team.



PAIN

Pain in children with cancer can be from many causes. Cancer cells in the blood or solid tumors in the body can cause bone or tissue pain. Some side effects of cancer treatment, such as mouth or skin sores, can be painful. Recovering from some surgical procedures can also be painful.

Helping Your Child to be More Comfortable

As parents, you know your child the best. It is very important to tell the health care team if your child has pain. The health care team will work to find out what is causing your child's pain. They will work with you to make a plan to decrease the pain as much as possible. There are many options that can be used to make your child as comfortable as possible. Pain medicines can be given in many different ways. There are also a variety of supportive comfort measures available to help your child. Different members of the health care team can support your child in unique ways to help manage both the physical and emotional aspects of pain.

Use of Pain Medicines

The type and amount of pain medicine and how it is given will depend on the type of pain, weight of your child, and whether or not your child can take medicine by mouth. The use of a tool, such as a pain scale, may be helpful in monitoring how much pain your child is having. Ask your health care provider about which pain scale they recommend. The goal is to make your child as comfortable as possible.

Late Effects of Cancer Treatment

Cancer treatment can cause side effects that happen years after treatment has ended. Examples of these effects include damage to the kidneys, liver, lung, heart, brain, reproductive organs, or a second cancer. The risk of late effects depends on the type and amount of treatment that your child receives. Your child needs regular follow-up care by a cancer specialist as they grow, and they will need continuing follow-up care throughout adulthood. This care will include getting tests done regularly to look for late effects. When your child completes treatment, ask your health care provider for a record of your child's cancer treatment. This record will help other health care providers know which long-term side effects to look for in the future.

FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG

Notes and Questions for Your Health Care Team

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Caring for Your Child and Family

Talking With Your Child About Cancer and Treatment

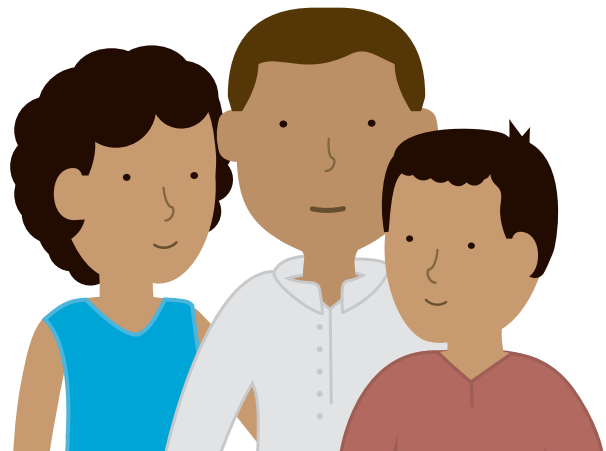
Often parents have a hard time telling their child about cancer. From years of experience, we know that not telling your child the truth can be harmful. Children need to know they can trust their parents to always tell them the truth. Children quickly sense when something is wrong and can react by feeling lonely and separated from family and friends. Children often imagine that things are worse than they are.

BENEFITS OF TELLING YOUR CHILD ABOUT CANCER

You may be asking yourself, “Why should I tell my child about cancer?” Many parents want to protect their child by not telling them any information they think might scare them. A child’s world is scarier when they do not know what is happening to them. The benefits of talking with your child about cancer and treatment are:

- Your child can build trust in both you and the health care team.
- Your child will know what to expect.
- Children fill in gaps of information with their imagination. Honest information helps correct any false ideas about cancer and cancer treatment.
- If your child understands the importance of doing some things (such as taking medicines, coming to the hospital, getting spinal taps, etc.) they may be more cooperative during treatments.
- Knowing and understanding their illness allows children to have a sense of control during times when they feel out of control.

Parents should consider their child’s age when choosing the words that are used to talk about what cancer is and how it is treated. Members of your health care team can help by talking with your child, and they can help you find ways to explain the diagnosis and treatment. You may use coloring books, teaching dolls, and other materials to help your child understand. Keep in mind that children learn from doing, seeing, and hearing things over and over.



You may need to tell your child about cancer more than once. As children grow older, they may need and want to know more about their cancer and the treatment that they received.

CANCER MYTHS: FACT OR FICTION?

Many myths about cancer exist that even adults believe. Talk to your child about what is true about childhood cancer. Ask your health care team if you are unsure of any information.

Is cancer someone's fault?

Many children, brothers, sisters, and parents believe cancer is caused by something they did, said, or thought. What we do, say, and think cannot cause someone to get cancer.

Is cancer contagious?

You cannot catch cancer from someone else.

Can cancer cause your hair to fall out?

Many children believe that the cancer causes their hair to fall out. Actually, the chemotherapy or radiation treatment causes hair to fall out. Remember to tell your child that in most cases, their hair will grow back when the treatment is finished.

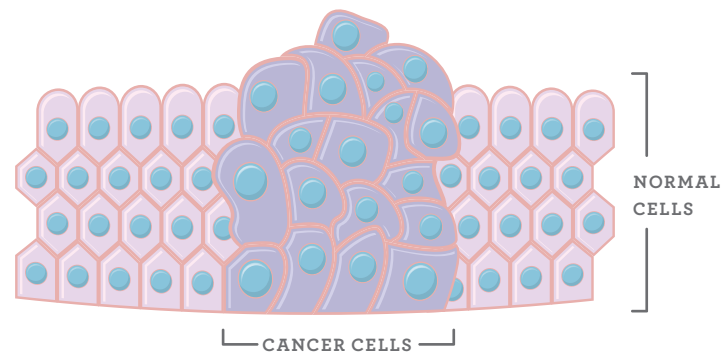
TALKING TO YOUR CHILD ABOUT CANCER

Here are some tips to use when talking with your child about cancer. Remember that the amount of information that you share will depend on your child's age. Keep in mind that honesty in answering your child's questions is important. Most hospitals have specially trained professionals, such as nurses, child life specialists, psychologists or psychiatrists, and social workers, who can help you find ways to explain cancer to your child.

HOW SHOULD I EXPLAIN CANCER TO MY CHILD?

To help your child understand cancer, first talk about how healthy bodies work. Cells are the building blocks of our bodies. Cells are very tiny, but are visible through a microscope. Every part of the body is made of cells (bones, blood, heart, skin, etc.). In healthy bodies, cells work together to help us look the way we look and feel the way we feel. Cancer cells grow out of control and crowd out normal cells.

When you talk with your child about cancer, ask what they think causes cancer. You will have a chance to correct any myths that your child may believe. Avoid using the words "bad cells" and "good cells" when talking about cancer so your child does not think they have bad cells because they were bad or did something wrong. Instead, use the words "sick cells" and "healthy cells." Below are some approaches to help explain the different types of cancer to your child.



TYPES OF CANCER

Leukemia

Bone marrow is a factory inside the bones where blood is made. The bone marrow makes three types of blood cells. Red blood cells carry oxygen to the body. White blood cells fight germs and infections. Platelets help stop bleeding. Leukemia is a cancer of the cells that make blood. Leukemia cells are sick white blood cells that do not work properly and crowd out healthy blood cells.

Lymphoma

The immune system is the body's defense system. The immune system finds cells that are not healthy or cells that do not belong in the body and destroys them. The immune system stores fighter cells, called lymphocytes, in lymphoid tissues in the body. Lymphoma is a cancer of the immune system and lymphoid tissues. The sick lymphoma cells do not work properly to protect the body and they crowd out healthy cells of the immune system.

Solid Tumors

Begin by explaining the normal job of the area of the body where the cancer is located. (For example, talk about how leg bones support your body and help you walk and do the things you like to do.) Then explain that a solid tumor is a lump of sick cells that are stuck together. These sick cells grow and crowd out the healthy cells, keeping them from doing their job.

TYPES OF TREATMENT

After talking about what cancer is, talk with your child about cancer treatments. Be specific about the types of treatment your child will receive. Explain that other children with different types of cancer may receive different types of treatment or different amounts of the same treatment. The most common types of treatment are described below.

Chemotherapy

Chemotherapy, often called “chemo,” is medicine that gets rid of fast growing cells. Cancer cells grow very fast. Chemotherapy is given to get rid of cancer cells. Our bodies also have healthy cells that grow fast. Chemotherapy sometimes hurts healthy cells too, but the healthy cells usually get better after therapy is completed.

When chemotherapy affects healthy cells, children may have side effects such as hair loss, upset stomach, mouth sores, fever, tiredness, or infection. Not all children have all of these side effects. The side effects that your child may have depend on the type of medicine that they get. Your health care team will talk with you about what to expect based on your child’s treatment plan.

Radiation

Radiation uses strong energy beams that you cannot see or feel. Machines focus these beams on the area of the body where the cancer is located. Radiation destroys cancer cells to stop them from growing and spreading. Radiation can also hurt healthy cells that are close to the cancer, but the healthy cells usually get better after therapy is completed. When radiation hurts healthy cells, children may have side effects such as hair loss, upset stomach, vomiting, mouth sores, tiredness, fever, and redness of the skin. Not all children have all of these side effects. The side effects that your child may have depend on the place where the radiation is given and the dose of radiation. Your health care team will be able to discuss with you what to expect based on your child’s treatment plan.

Surgery

During surgery, a doctor takes out all or part of the cancer. Surgery may also be done to give the child a tube (central line) for getting intravenous medicines and fluids during treatment. Some children also have surgery for placement of a feeding tube (G-tube) to help them get the nutrition they need during their treatment. Your health care team will explain the exact surgery that your child will receive. Your child will be given a special medicine (anesthesia) so they cannot feel or see anything when the surgery is being done.

Helping Your Child Cope

FEELINGS

After talking with your child about cancer and treatment, talk with your child about feelings. Children with cancer may feel angry, guilty, sad, lonely, and scared, but many times they will also feel happy. Assure your child that any feelings they have are normal. Young children often benefit from learning names for their feelings.

Be honest with your child about your feelings. Children can sense when something is bothering you. Sharing your feelings with your child tells them that it is okay to feel upset or angry.

Cancer creates many changes and challenges for children and their families. As a parent or caregiver you may be asking:

- What does my child know about cancer?
- How will my child feel about the treatment?
- How can I support my child?

Children of different ages understand and react differently to cancer and its treatment. Your child's personality, normal coping style, support system, treatment plan, as well as age or developmental level will affect how your child copes with cancer.

When children are faced with stress, their normal behaviors may change. They often become more dependent on adults, or they may act younger than their age (baby talk, wetting pants after being potty trained, tantrums, etc.). Your child may not know how to handle the many feelings that have been caused by the cancer diagnosis.

You are a very important part of your child's life for many different reasons. You know what your child has experienced in the past and how your child usually handles stress. You can help the health care team to better understand your child. You and the health care team can work together to find new ways to help your child cope with cancer and treatment.

The following section describes common responses to stress for children of different ages. The section also contains specific suggestions for how to help children in each age group cope.



Infants (birth – 12 months)

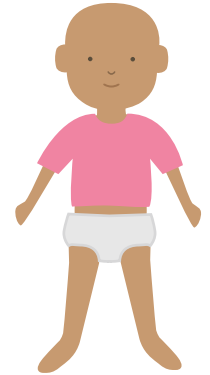
Infants look to their parents/caregivers to meet their needs. They rely on adults for food, comfort, play, and care. Infants learn about the world around them through their senses (i.e., they can sense new smells, colors, tastes). They trust in people and things that are familiar. Infants have no concept of the meaning of cancer or its implications. They do respond to new people and to the environment around them.

ISSUES	WAYS TO SUPPORT YOUR INFANT
Separation from familiar people	<ul style="list-style-type: none"> · Be with your infant as much as possible. · Leave a piece of clothing with your smell on it if you need to leave. · Rock or hold your infant when in the hospital. · Have familiar people care for your infant. · Limit the number of people and voices in the room.
Development	<ul style="list-style-type: none"> · Let your infant explore toys with their hands and mouth. (Check for small pieces that may be choking hazards, and clean toys regularly to prevent infections.) · Use gentle touch and massage to comfort your infant. · Talk to and play games, like peek-a-boo, with your infant as you would at home. · Provide music for stimulation or to soothe your baby.
Sense of Safety	<ul style="list-style-type: none"> · Keep your infant's crib safe by keeping railings up in the locked position. · Ask that any procedures be done in the treatment room. · If your child needs to have a painful procedure done (such as drawing blood from the finger or arm) this should not be attempted while your infant is asleep. Wake your infant first and provide comfort for them during the procedure. · Continue familiar feeding, bedtime, and bath-time routines, like rocking, touching, and singing.

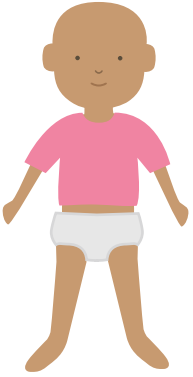
Your child life specialist, social worker, or other health care team members can provide you with additional suggestions.

Toddlers (1 year – 3 years)

Toddlers are beginning to want to do more on their own. Your toddler’s favorite words may be “me do” or “no.” Growing toddlers need to be able to do some things by themselves to promote a sense of control. Toddlers show you how they feel by their actions because they do not have the words to describe their feelings. They have a hard time understanding how the body works. Toddlers tend to think that they make things happen. They can create their own false ideas about how they got sick and what is happening to them (for example, they may be thinking “I hurt because I was bad”).



ISSUES	WAYS TO SUPPORT YOUR TODDLER
Fear of separation	<ul style="list-style-type: none"> · Be with your toddler as much as possible. · When you leave, tell your toddler where you are going and when you will be back. · When you are gone, leave something of yours, like a picture or a piece of clothing, for your toddler to keep until you return.
Fear of stranger	<ul style="list-style-type: none"> · Have familiar people care for your toddler. · Provide security objects such as a blanket or stuffed animal.
Loss of control	<ul style="list-style-type: none"> · Let your toddler make choices whenever possible. For example, ask your toddler “Would you like apple juice or orange juice?” · Do not offer a choice when no choice exists. Instead of asking “Are you ready for your medicine?” say “It’s time for your medicine. Would you like juice or water to drink after you take it?” · Give your toddler a job to do, such as “Hold this BAND-AID®.” · Let your toddler play and be in control of the game or activity.
Loss of normal routine	<ul style="list-style-type: none"> · Try to keep eating, sleeping, and bathing routines as normal as possible. · Let your toddler play with favorite toys.



Toddlers (1 year – 3 years, continued)

ISSUES	WAYS TO SUPPORT YOUR TODDLER
Behavior changes	<ul style="list-style-type: none">· Give your toddler safe ways to express anger and other feelings, such as modeling clay, painting, or building blocks.· Tell your toddler that it is all right to feel mad or sad.· Spend time with your toddler and offer reassurance.· Set limits with your toddler and discipline when needed.
Fear of treatment, medicine, tests, vital signs	<ul style="list-style-type: none">· Assure your toddler that they did nothing wrong.· Keep security objects, such as blankets, pacifiers, or a favorite toy nearby.· Tell your toddler what will happen just before the treatment or procedure.· Use simple words, pictures, or books to tell them what will happen.

Your child life specialist, social worker, or other health care team members can provide you with additional suggestions.

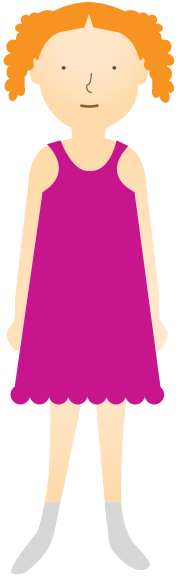
Preschoolers (3 years – 5 years)

Preschoolers take pride in being able to do things for themselves. They often say: “I can do it.” Preschoolers are learning more words to tell you what they think and feel. However, they often use their play to tell you these same things. They may view the hospital and treatment as punishment for something they did wrong. They often get confused by adult words and make up reasons for the things that happen.



ISSUES	WAYS TO SUPPORT YOUR PRESCHOOLER
Magical thinking (Made-up reasons for what happens)	<ul style="list-style-type: none"> · Tell your preschooler what will happen a little before the treatment. · Don't use terms that may confuse your preschooler; for example, a CAT Scan has nothing to do with a cat. · Use simple words, pictures, or books to tell your preschooler about what will happen.
Fear of harm to their body and the unknown	<ul style="list-style-type: none"> · Let your preschooler play with toy medical kits and safe medical supplies, such as a blood pressure cuff.
Loss of control	<ul style="list-style-type: none"> · Allow your preschooler to make choices whenever you can. For example, ask your preschooler “Would you like apple juice or orange juice?” · Do not offer choices when choices do not exist. Instead of asking “Are you ready for your medicine?” say “It's time for your medicine. Would you like juice or water to drink after you take it?” · Give your preschooler a job to do, such as “Hold this BAND-AID®.”
Loss of normal routine	<ul style="list-style-type: none"> · Praise your preschooler for doing things independently, such as dressing, brushing teeth, and feeding.
Behavior changes	<ul style="list-style-type: none"> · Give your preschooler time to adjust to new changes. · Use play to help your preschooler show feelings.

Your child life specialist, social worker, or other health care team members can provide you with additional suggestions.



School Age Children (6 years – 12 years)

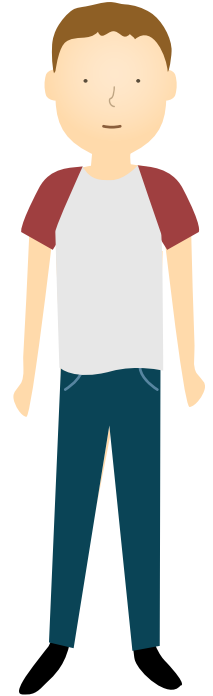
School-age children take pride in being able to do most things by themselves. They usually enjoy school because it helps them to learn and master new things. Their friends are becoming more important influences. School-age children are able to understand cause and effect and have a better sense of time. They have more words to describe their bodies, thoughts, and feelings. School-age children can also understand more of how their bodies work. However, they still may be confused by medical words.

ISSUES	WAYS TO SUPPORT YOUR SCHOOL-AGED CHILD
Loss of control	<ul style="list-style-type: none"> · Allow your school-aged child to make choices whenever practical/possible. · Do not offer choices when no choices exist. · Give your school-aged child a job to do. · Let your school-aged child practice things that are new and scary. · Let your school-aged child go to school or do schoolwork and activities whenever possible. · Provide games, play, and activities.
Being away from friends and school	<ul style="list-style-type: none"> · Encourage your school-aged child to stay in touch with their friends via email, phone calls, cards, and letters. · Let friends visit when your school-aged child feels well enough (following the recommended guidelines).
Fear of harm to the body and unknown	<ul style="list-style-type: none"> · Use simplified explanations, pictures, or books to tell your school-aged child what will happen. · Tell your school-aged child what will happen a few days before the treatment, if possible. · Let your school-aged child play with safe medical supplies, such as a blood pressure cuff.

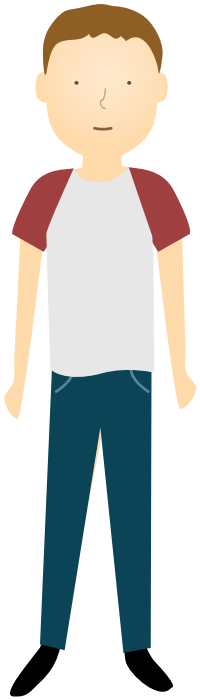
Your child life specialist, social worker, or other health care team members can provide you with additional suggestions.

Teens (13 years – 18 years)

Teens are beginning to see themselves as individuals in the world. They are striving to be independent from the adults around them. As teens strive to think and act for themselves, their peers become even more important. Teens want to be like their friends and are concerned with how they are viewed by others. Illness and treatment cause teens to be different from their peers when they are trying very hard to be the same. Teens are able to understand cause and effect, and can also see things from many points of view.



ISSUES	WAYS TO SUPPORT YOUR TEEN
Loss of control	<ul style="list-style-type: none"> · Allow your teen to make choices whenever you can.
Loss of independence	<ul style="list-style-type: none"> · Let your teen be active as possible in social and school activities. · Encourage your teen to become involved in their treatment plan. When possible, include them when talking to the health care team about the plan. · Encourage your teen to do their own self-care as much as possible, such as bathing, dressing, grooming, and eating.
Body image	<ul style="list-style-type: none"> · Give your teen chances to talk about physical and emotional changes. · Tell your teen that having feelings about illness and treatment is normal.
Self-esteem	<ul style="list-style-type: none"> · Point out things that your teen does well. · Allow your teen to do things that make them feel good about themselves.
Loss of privacy	<ul style="list-style-type: none"> · Respect that teens may need to do some things by themselves when possible, such as using the bathroom, making phone calls, or reading and sending email. · Offer your teen private time.



Teens (13 years – 18 years, continued)

ISSUES	WAYS TO SUPPORT YOUR TEEN
Separation from peers	<ul style="list-style-type: none"> · Encourage time with peers. · Allow friends to visit or call in the hospital or at home (following the recommended guidelines).
Concern for the future	<ul style="list-style-type: none"> · Answer questions openly and honestly. · Help your teen plan for the future. · Encourage your teen to keep doing normal things whenever possible, such as attending school.
Behavior changes	<ul style="list-style-type: none"> · Give your teen safe ways to express feelings, especially anger. Helpful activities may include talking, going for a walk, or writing. · Assure your teen that all feelings are normal, including guilt, fear, and sadness.

Your child life specialist, social worker, or other health care team members can provide you with additional suggestions.

Caring for Your Child at Home

INFECTION

Children who are being treated for cancer are at risk for serious infections. If your child develops a fever, chills, or does not look well, it is important to **call your health care provider right away**. If your child has a serious infection and does not receive medical care right away, they could get very sick and this could be life-threatening. Your child may need to be admitted to the hospital or come to clinic for antibiotics to treat the infection. Before antibiotics are started, blood cultures may be taken to see if bacteria are in your child's blood. Blood culture results may take up to 72 hours. Until the blood culture results are known, your child's health care provider may prescribe antibiotics that are known to be effective for the most common types of bacteria in children with cancer. If bacteria are present, the culture will help your health care provider know whether or not to change the antibiotics.



The most common types of infections in children with cancer are bacterial, opportunistic, and viral infections.

Bacterial Infections

Bacteria can cause serious infections in children with low white blood cell counts. Bacteria live on the skin and inside the body. A healthy immune system and a normal white blood cell count usually prevent bacteria from causing serious infections. However, when the white blood cell count is low, the chance of getting an infection goes up. Children who have central lines also have a higher risk of getting a bacterial infection in the blood.

Opportunistic Infections

When the immune system is not working well, common germs that are usually harmless now have an opportunity to cause infection. These infections include those caused by mold or fungi, and a type of pneumonia called pneumocystis. Your health care provider may give your child medicines to help prevent opportunistic infections. For example, your child may take a medicine called Bactrim™ or Septra® to help prevent pneumocystis pneumonia.

Viral Infections

Children who receive cancer treatment can get common viral infections, such as colds and diarrhea. Some viral infections, such as chickenpox and shingles, may cause more serious illness in children with cancer that may require treatment or hospitalization.

For more information, refer to the "Treatment and Effects" and "Information from My Hospital" sections of this handbook, or ask your health care team.

Chickenpox and Shingles

WHAT ARE CHICKENPOX AND SHINGLES?

Chickenpox is caused by the varicella virus. It is spread through the air and is very contagious. The infection usually starts with 1 to 2 days of flu-like symptoms, such as fever and feeling tired. Small itchy red spots with a clear, fluid-filled center then appear on the face, head, or chest. The spots spread down over the arms and legs. New spots can develop for 3 to 5 days. After a few days, the spots will dry up and form crusts. For children who are receiving cancer treatment, chickenpox can be serious because the immune system is not working well.

Shingles is another type of infection that is caused by the varicella virus. The varicella virus stays in the body long after a person has recovered from chickenpox. If the immune system is not working well, such as during cancer treatment, the virus may become active again. Shingles usually appear as a patch of red blisters that form a line on the skin of the back, chest, or other part of the body. Shingles can be painful and cause a deep burning feeling.

IF YOUR CHILD GETS CHICKENPOX OR SHINGLES

If your child has symptoms of chickenpox or shingles, **call your health care provider right away.**



The health care provider may order medicine to be taken by mouth or I.V. to help control the infection.

Your child may need to be admitted to the hospital for observation and treatment.

To protect other patients from exposure to chickenpox or shingles, ask your health care provider if you should use a separate entrance to the clinic or hospital or follow other precautions while your child has chickenpox or shingles.

IF YOUR CHILD IS EXPOSED TO CHICKENPOX OR SHINGLES

Exposure has occurred if your child was:

- In the same room with a person who had chickenpox, or
- In the same room with a person who comes down with chickenpox within 1 to 2 days after being with your child, or
- In direct contact with the blisters of a person with shingles



If your child is exposed and has not had the chickenpox or the chickenpox (varicella) vaccine, **call your health care provider right away.** It is possible your child will need to get a medicine to protect against chickenpox. This medicine has antibodies that help

to prevent or decrease the severity of chickenpox. For the medicine to work, your child must get it as soon as possible after exposure.

If your child is exposed but has already had chickenpox or the chickenpox vaccine, they may have antibodies to fight the virus, and may not need to get the extra medicine to protect against chickenpox. Ask your health care provider if your child is at risk for getting chickenpox.

For more information about chickenpox and shingles, refer to the “Information from My Hospital” section of this handbook, or ask your health care team.

PREVENTION OF INFECTION

Whether at school, home, or in your community, your child will be exposed to germs, including bacteria, fungi, and viruses. We all have germs on our skin and in our mouth and intestines. Germs can also be found in the environment and in people with infections. Some suggestions for preventing infections in your child with cancer are described below.



Hygiene

Encourage your child, family members, and visitors to wash their hands frequently with soap and water or use a hand sanitizer to prevent the spread of germs from one person to another. Keeping the hands clean is the most important way to prevent infection. Encourage your child not to share cups, eating utensils, or toothbrushes with other people.

Screen Visitors and Playmates for Infections

Your child should play and visit with other children, but be sure to ask ahead if the playmate or visitor has been exposed to or has an infection. Anyone who has a fever, runny nose, cough, diarrhea, or rash should not visit or play with your child.

Dental Care

Keep your child's teeth, mouth, and gums clean. Brush the teeth after each meal and before bed with a soft toothbrush and toothpaste. Running warm water over the toothbrush will make it softer.

Check with your health care provider before taking your child to the dentist. Checking your child's blood counts before any dental work is important. Your health care provider may want to prescribe antibiotics before dental work, or the dental work may need to be postponed.

Caring for Animals

Many children with cancer have pets. Your child should not clean animal cages (such as a bird cage or turtle aquarium) or empty cat litter boxes. Stool and urine from animals can carry germs that can be spread to your child. If you live on a farm, talk with your health care provider about any additional precautions that may need to be taken when working with animals.

Vaccinations

Your child should not receive any live vaccines, such as the MMR (measles, mumps, rubella) vaccine, the varicella vaccine, or the oral polio vaccine, while on treatment. Live vaccines can cause illness in children who are at increased risk of infection. Vaccines that are made of proteins may be safe for your child, and flu shots are usually encouraged. Talk to your health care provider before your child receives any vaccines.

Other children in your family generally can and should receive their usual vaccines. Check with your health care team if your other children are due to receive live vaccines, such as MMR or varicella, to be sure there are no restrictions.

SKIN CARE

Chemotherapy and radiation can affect the skin. Some medicines (such as methotrexate, doxorubicin, busulfan, thiotepa, Bactrim™ and Septra®) and radiation make the skin more sensitive to sunlight. Any area of the skin that receives radiation will always be sensitive to sunlight. Sunburn can lead to blisters, which can get infected. Skin damage from the sun can also lead to skin cancer.

Remember to protect children from sunburn when the skin is exposed to the sun, even on cloudy or hazy days. Sand, snow, concrete, water, and high altitudes all increase the risk of sun damage. When outdoors, your child should wear protective clothing (hat, long pants, long sleeves) and sunscreen (look for SPF 35 or higher on the label). If your child is outdoors for a long period of time, reapply the sunscreen after a few hours. It is best to plan outdoor activities in the morning or late afternoon. Avoid outdoor activities from 10 a.m.–2 p.m. when possible, since the sun's rays are usually most intense during these times.

GIVING ORAL MEDICINES

Your child may need to take chemotherapy and other medicines by mouth. Always check to make sure your child is taking the right medicine in the right amount. Ask your health care provider or pharmacist about:

- Whether the medicine should be taken with food or on an empty stomach



- The best time to take each medicine
- What to do if your child vomits a dose of their medicine
- Any special precautions that need to be followed when preparing and giving oral chemotherapy at home

Here are some tips for helping your child to take medicine by mouth:

- Some medicines can be crushed and put in a small amount of food or fluid (applesauce, ice cream, juice, or flavored syrup). Use only a very small amount of food or fluid so that your child can swallow all of it. Check with your pharmacist to make sure your child's medicine will still work correctly if it is crushed.
- Do not hide medicines in your child's favorite foods. Your child may not want to eat these foods in the future.
- For older children who can swallow a pill, some medicines can be crushed or split in half and put into a gelatin capsule to make them easier to swallow.

For more information about the safe handling of chemotherapy, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Many families are interested in using complementary and alternative medicine (CAM) for their child with cancer. There are many different types of CAM therapies. Some may be safe for children with cancer, while others may interfere with treatment, or be unsafe for children who have low blood counts. It is important to discuss any plans for using CAM with your child's health care team.

Herbal and Natural Products

You may wish to give your child herbal or natural products (vitamins, homeopathic remedies, supplements). It is important to discuss this with your child's health care team before starting any herbal or natural product. While some of these products may be safe, some natural products and vitamins may interfere with how well chemotherapy works. Herbal and natural products may contain bacteria or fungi, increasing your child's risk for infection. Some products may have side effects that can interfere with cancer treatment. It is very important to talk with your child's health care team before giving your child any vitamins, remedies, or other natural products.

Other CAM Therapies

Some types of CAM therapy may be helpful in managing the symptoms related to cancer treatment. Some CAM therapies are designed to reduce stress and help the child with cancer feel more relaxed and comfortable. Examples of CAM therapies that are sometimes used in children with cancer include yoga, imagery, art therapy, meditation,

massage, aromatherapy, and music therapy. Talk with your health care team about any type of CAM therapy that you would like to use in your child's care. It is important for your child's health care providers to be aware of all types of therapies that your child is receiving in order to provide your child with the safest and most effective care possible.

NUTRITION

A healthy diet is an important part of helping your child's body to grow, heal, and work well. The body needs protein, carbohydrates, fats, vitamins, and minerals. As your child progresses through treatment, their appetite will change. Cancer treatment can cause changes in taste. For example, your child may complain that some foods have a metallic taste, and their usual food preferences may change.

Steroids may cause your child to overeat and temporarily gain weight. In some cases, your health care team may want to limit further weight gain. You can talk with your health care provider or dietitian if you are worried about your child's weight gain. Together, you can make a plan to help your child get enough to eat, but with less fat and calories.

You may notice changes in your child's appetite and food choices. Your child may not like a past favorite food. New foods may taste good. Avoid forcing any food on your child. The appetite usually returns to normal after a specific phase of treatment is over.

If your child cannot eat enough by mouth to keep the body working well, a special nutrient formula may be given through a tube. The tube may be placed in the nose and go into the stomach (N.G. tube or nose tube). A tube can also be surgically placed right into the stomach through the wall of the abdomen (G-tube or "PEG"). The formula will give your child fluid, calories, protein, vitamins, and minerals. Some of these formulas are available at the grocery store, such as Pediasure®. Others may be supplied by the hospital. If your child has a feeding tube, you will be taught how to use the tube at home.

If your child cannot tolerate tube feedings or there is another medical reason to prevent the use of a tube, a different nutrient solution can be given through an I.V. This special solution is often called total parenteral nutrition (TPN or "hyperl"). TPN is made of two liquids. One is a yellow liquid that contains protein, carbohydrate, minerals, vitamins, and electrolytes. The other is a white liquid that contains fats. TPN can be given at home. In general, TPN will only be used if your child has nausea, vomiting, diarrhea, or another medical problem that prevents the use of feeding through a tube.

CARING FOR CENTRAL LINES

Special care is needed to prevent the central line from becoming infected. Always wash your hands before touching the line or dressing. Carefully follow all instructions



from your health care team about caring for your child's central line. These may include instructions for changing the dressing, flushing the line, and giving medicines. **Call your health care provider right away** if your child develops:

- Redness, swelling or pus around the insertion site
- Shaking chills after flushing the central line
- Pain at the central line site
- Fever



If your child has an external line, never use scissors near the line or the dressing. If you see a break or leak in the line, clamp the line above the break right away. Take your child to the hospital right away to have the line fixed.

If you are flushing the line and you feel resistance (fluid is hard to push in), do not force it. Check to make sure the line is not twisted or clamped and try again. If you still feel resistance, call your health care provider.

For more information about central lines, refer to the "Treatment and Effects" section of this handbook. For more information about caring for central lines at your hospital, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

SCHOOL

During treatment, your child needs to continue to learn, grow, and interact with their peers (friends). Going to school is an important part of your child returning to a normal routine. School also helps children to feel good about themselves and hopeful for the future. Your health care provider will talk with you when your child is ready to go back to school. To help ease the transition, your child life specialist or another member of your health care team may be able to go to your child's school to talk with the classmates and explain what cancer is and how it is treated. Tell your child's teacher to call you if any child in the class gets a contagious illness like chickenpox.

Many children find it hard to go back to school, especially if they have changes in their body. Hair loss and weight loss or weight gain are common concerns. Tell your health care provider if your child is worried about going back to school. Your child life specialist, social worker, psychologist or nurse may be able to help. If your child is having problems doing school work, ask for extra help. Two laws in the United States allow for children with cancer to get a special education plan, which may



include extra help. These laws are called IDEA (Individuals with Disabilities Education Act) and Section 504 of the Rehabilitation Act. Talk with someone from your health care team to see how these laws, or the laws in your country, may apply to your child.

If your child is not able to go to school, talk with your child's teacher. Your health care provider can write a letter to the school to explain your child's diagnosis and treatment. Your child's teacher can send schoolwork home and find ways to keep your child in touch with the other children in the class. Your school may also provide homebound instruction, if needed. A tutor may come to your home to help your child with school work.

Caring for the Whole Family

COPING WITH YOUR FEELINGS

Since the time of your child's diagnosis, your lives have not been the same. The diagnosis of cancer brings changes to your life and the lives of the whole family. Every family is different. Each family has ways to cope with stressful experiences. Many families have told us about feeling fear, anger, depression, and guilt. All these feelings are common human emotions. You are not alone. Talking with family and friends, a member of the health care team, or another parent of a child who has cancer may be helpful. By sharing these feelings, you may find it easier to cope with the changes you are experiencing.

Fear

The time of diagnosis is often the most difficult. The fear of the unknown and what a cancer diagnosis means for your child may be overwhelming. This experience may be your child's first hospitalization. Dealing with the stress of your child adapting to a new and sometimes frightening environment may be difficult.

You may also have fears about treatment, finances, or how you will help your child to cope with cancer. Talking about these fears and getting them out in the open can be helpful. The health care team is here to listen to your concerns and help you.

Anger

At times you may feel very angry at what is happening. Some families are angry with God or fate for singling them out. Some are mad at the health care team for not finding an answer to what is happening with their child. You may even feel angry with your child for getting sick and turning your life upside down. Feeling angry is a normal reaction. However, taking your anger out by yelling, fighting or other violent actions is not a healthy way of coping. Finding a safe outlet to let off steam may be helpful. For

example, some parents find that taking a walk or talking with a trusted friend helps ease the tension. Many parents also find it helpful to talk with a psychologist, social worker, or chaplain.

Guilt

Parents often feel guilty for not knowing that their child was sick. Many parents wonder if they did something to cause their child to get cancer. Brothers and sisters may also feel guilty that they are healthy, and they may worry that they caused the illness by something that they did or thought. For example, a brother or sister may be thinking “We had a fight and I wished he would die—and now he has cancer!” Everyone in the family needs to be assured that they did not cause the cancer, nor could they have done anything to prevent it.

Depression

People use depression to describe a range of emotions and behaviors. Feeling “blue” or sad is a normal reaction to the diagnosis of cancer and the treatment demands. The illness may also require changes in family routine and bring feelings of social isolation. These changes and losses may produce grief reactions. You may notice symptoms of grief, such as crying spells, decreased appetite or compulsive eating, lack of interest, decreased energy, lack of concentration, poor problem solving, and physical symptoms such as tightness in the chest or headaches.

With the support of family, friends, and the health care team, most parents are able to work through these emotions and use coping skills that are needed to meet care demands. Individual or family counseling allows parents a way to discover their inner strengths. Sometimes parents find that their emotions are so overwhelming that they feel they cannot cope with the demands being placed on them. When other life stressors, such as loss of a job, moving, marital problems, divorce, emotional problems, or substance abuse existed prior to the diagnosis, the situation may be more difficult. It may help to discuss your feelings with a trusted member of the health care team. Counseling and medications may be needed and are available.

COPING WITH YOUR CHILD’S ILLNESS

Some suggestions to help you cope with your child’s illness include:

- Make a special effort to find private time to talk with your spouse or partner, or with a close friend. Try to talk about things other than your sick child.
- Try not to talk about your child in their presence unless they are included in the conversation.
- Find ways to reduce stress. Many parents find it helpful to take a walk, read, or

spend time with trusted friends. You know what works best for you.

- Try to take turns with your spouse or other support person when staying with your child in the hospital or coming for clinic visits.
- Both parents can be involved with the child's treatment. Sharing responsibilities reduces the gap that may grow between parents when one is more involved in care than the other.
- Allow family members and friends to help. Suggest specific ways that they can help you, such as asking them to shop for groceries, cook, clean, or take your other children to and from school.
- Identify a contact person who stays in direct communication with you and is willing to update other family members and friends about your child's condition. This will save you from repeating the same information over and over to many different people. Some families find it helpful to set up a website, blog, or other method of electronic communication to keep others informed.
- Ask a member of the health care team for help and support.
- Talk to other parents of children with cancer.
- Attend a support group.
- Talk to your health care provider about whether or not counseling and/or medication is appropriate for you.

IMPACT OF THE CHILD'S CANCER ON A MARRIAGE/RELATIONSHIP

A chronic illness can quickly turn a family's life upside down. Parents often become exhausted trying to cope with the needs of the child and the rest of the family; financial problems are common. Many parents try to continue to work at their jobs and keep the home routine as normal as possible. Many couples feel a strain on their relationship. Parents often say that they do not have time for each other. They may feel angry and frustrated with what has happened to their child. Three things may help prevent the breakdown of a marriage/relationship: respecting coping styles, maintaining communication, and accepting changing roles.

Respecting Coping Styles

Each person responds differently to stress. Some parents may withdraw, others may cry or get angry, while others may cope by gathering information. Parents need to learn and respect the different ways each has in coping with the child's illness. Try to understand where your partner is in accepting what is happening.

Maintaining Communication

The key to any successful relationship is communication. The need to talk about feelings,

fears, appreciation, and information is even greater during times of stress. Silence can make you feel separated from your partner. By sharing feelings and information you can stay connected and be better able to make decisions.

Accepting Changing Roles

The demands of illness and treatment can change the roles of family members. The change in roles can cause stress within a marriage or family. Some temporary role changes may be necessary to support the ill child. Some role changes may become permanent, if the changes help improve how parents or family members work together.

Parents Working Together

Some suggestions to help parents work together when they have a child with cancer include:

- Learn about the diagnosis and treatment together.
- Work together to provide care and attention for your other children.
- Share feelings with each other.
- Be sympathetic and understanding toward one another, avoiding blame and criticism.
- Accept the help of family, friends, and neighbors.

SUGGESTIONS FOR SEPARATED OR DIVORCED PARENTS

While separation or divorce is difficult for most families, problems may get worse when a child is diagnosed with cancer. The most important thing to help is to stay focused on your ill child and their brothers and sisters. Maintaining this focus can help reduce other problems that may have existed in your family before your child's diagnosis, or that may become worse after the diagnosis.

Family boundaries and routines can become blurred when separated or divorced parents pull together to care for their child after diagnosis. In stepfamilies, it is important for stepparents to allow biological parents time and space to work together to make treatment decisions and to care for the ill child. This can be a hard time for stepparents, as they may be unsure about how to help. It is important to remain flexible and supportive of each other so that you can deal with needed changes to your parenting plans as your child begins treatment.

If your relationship with your "ex" is difficult, you may want to seek additional help from your social worker or psychologist to help cope with your feelings. In addition, your child with cancer and your other children may need additional support to cope with these added changes to their family, especially if the separation or divorce recently occurred.

Work together and do not allow the stress of divorce or separation to affect your child's care. Though the marriage or relationship has ended, your responsibility for parenting continues. Good communication helps parents get the best care for their child.

Some suggestions to help avoid problems include:

- Remember to focus on your ill child as you negotiate new demands on your relationship and previous shared parenting plans.
- Place a copy of divorce decrees, custody, and visitation rights in your child's medical record.
- Meet together with the health care team to avoid confusion about the plan of care.
- Ask your health care provider to routinely email both parents important information, especially when both parents cannot attend clinic or hospital visits. This way you will know that you both have received the information accurately.
- Ask for two copies of all teaching materials so both parents will have the same information.
- Develop a family communication plan to make sure important health information is shared when the child moves between households.
- If you or your former partner have remarried, remember to include stepparents in teaching, as they will be involved in caring for the child at home.
- Talk with a member of the health care team if you notice changes in your child with cancer, changes in your other children, or if you are having difficulty working with your "ex."

IMPACT OF CANCER ON BROTHERS AND SISTERS

Brothers and sisters of a child with cancer may have many different feelings and responses. Often they have needs similar to their sick brother or sister. They may feel upset, scared, and unsure of what the future holds. Brothers and sisters may fear the word cancer and worry about death. Regardless of age, they will sense a change in their family life.

While your other children may feel sad and worried about their sick brother or sister, they may also feel some resentment or anger. Mom and Dad are spending all of their time with or talking about the sick child. Friends and family send the sick child gifts and money. The other children in the family, especially young ones, may feel jealous. Brothers and sisters may also feel sad and cry easily. Often brothers and sisters have problems of their own, such as depression, trouble sleeping, physical complaints, or problems in school.



How to Help Brothers and Sisters

The following suggestions may be useful in helping your other children cope with their brother's or sister's illness:

- Try to spend time alone with your other children, doing things that are of interest to them.
- Let your other children know they are still loved and important to you.
- Explain the diagnosis, treatment, and side effects that their brother or sister may experience. What you tell them will depend on their ages and ability to understand. Assure them that cancer is not contagious and they are not responsible for their brother or sister getting cancer.
- Take your other children with you to the hospital to help them feel involved in the care and treatments of your sick child. This may help to decrease their fears and increase feelings of closeness with their brother or sister.
- If possible, ask a loving friend or relative to stay in your home, rather than sending your children elsewhere.
- Allow your children to help with chores at home. This may help them feel needed and can also help you.
- Talk with your children's teachers. Teachers can be supportive to your children and let you know about any school-related problems.
- Ask for help from a member of the health care team, such as a child life specialist, social worker, psychologist, or child psychiatrist.

IMPACT OF CANCER ON GRANDPARENTS

Grandparents have a variety of responses when they hear that their grandchild has cancer. Like you, they may feel shock and disbelief. Grandparents may feel guilty for living a long life. They may also feel they are responsible, and may worry that they in some way passed cancer through the family. Grandparents may also feel sadness, not just for their grandchild, but for their son or daughter as well.

Grandparents can be a great help to you and your family. If they are in good health and can be with you, they can relieve you in the hospital or help you at home. A grandparent may also give your other children the attention, comfort, and love that they need.

Grandparents can also serve as contact persons. They can give information to other family members, so you don't have to spend as much time on the phone or emailing. Including grandparents in meetings with the health care team can help them to understand the plan of care for their grandchild.



DISCIPLINING A CHILD WHO HAS CANCER

From the moment a child is diagnosed with cancer, the normal family routine is disrupted. The child becomes the center of attention of family members and friends. Often, the child receives many gifts. Although the child may feel sick, gifts and attention are still fun. Children can get used to being “special” and want the special treatment to continue.

Discipline problems are most common when the special attention stops and normal activities resume. The illness itself can also interfere with discipline. Children are likely to act more immature and more dependent when they feel sick. Pain and the side effects of treatment can make any child irritable. Many medicines, such as steroids, can also cause irritability. These behavior changes can make it difficult to know what is reasonable to expect of your child.

Many parents feel helpless and guilty when they see their child suffer. You may feel the need to make up for the suffering by giving special privileges. These feelings are normal. However, becoming too lenient can also be a problem. Children expect and need adults to give them structure. Rules and limits provide security. If a parent is too lenient, the child may think the illness is worse than they have been told. The child may even think that the condition is hopeless.

Keep in mind the following guidelines when deciding on how you can provide limits for your child:

- Set clear, consistent, and age-appropriate limits.
- Adjust your expectations to your child’s current condition. If your child is not feeling well, “please” and “thank you” may not be reasonable with every request.
- Use alternatives to spanking. Try using a “time out” approach or taking away privileges.
- Use praise and attention to reward good behavior.

Resources

Many resources are available at your hospital and clinic and in your community to help your child and family through this time. Types of resources available may include information, support, financial assistance, housing, and transportation. The health care team needs you to let them know what types of resources would be most helpful to you. If you or your child needs something, let your health care team know.

Internet Sites

The Internet is a resource that you may find helpful. The Children's Oncology Group, your health care team, hospital, or clinic does not guarantee the accuracy of the content on these sites. If you have questions about what you read on any of the sites, please ask someone on your health care team to discuss the content with you.

The following web sites have information about pediatric cancer and cancer-related resources:

CHILDREN'S ONCOLOGY GROUP

www.childrensoncologygroup.org

Online information regarding diagnosis, treatment, clinical trials, coping with cancer, and follow-up care for children, adolescents, and young adults with cancer and their families, from the health care professionals, parents, and survivors associated with the Children's Oncology Group, a network of more than 200 hospitals that form the world's largest pediatric cancer research organization.

CURESEARCH

www.curesearch.org

CureSearch.org is an online resource for patients, their families and support systems. The website provides up-to-date information about the various types of children's cancer along with research trials; definitions and descriptions of tests, procedures, and treatments; and information to help families manage the emotional aspects of caring for a child with cancer.

AMERICAN CHILDHOOD CANCER ORGANIZATION

www.acco.org

Founded by parents of children with cancer, the American Childhood Cancer Organization offers information, support, and advocacy for children and adolescents with cancer and their families through local affiliates and at a national level.

CARINGBRIDGE

www.caringbridge.org

CaringBridge provides personal, private websites free of charge for people experiencing significant health challenges. These websites allow patients and families to keep friends and loved ones informed, and to receive messages of encouragement and support. Families have control over website privacy levels, including an option to set a site password or approved visitor list.

FERTILE HOPE

www.fertilehope.org

Fertile Hope provides information about reproductive options for those at risk for infertility due to cancer treatment.

HOPE PORTAL

www.searchHOPE.org

Web portal developed by Childrens Hospital Los Angeles HOPE Resource Center that serves as an Internet gateway to childhood cancer information and services, providing links to other sites. A search within the portal can be customized by user, the disease or condition, and the age group of the patient. Users can access a tutorial about how to use a computer or the Internet.

NATIONAL CANCER INSTITUTE (NCI)

www.cancer.gov

Cancer-related information from the National Cancer Institute, the United States federal government's primary agency for cancer research.

PEDIATRIC BLOOD AND MARROW TRANSPLANT CONSORTIUM

www.pbmtc.org

Information for families of children undergoing blood and marrow transplants from the Pediatric Blood and Marrow Transplant Consortium, a network of more than 100 hospitals that form the largest existing research organization focused on pediatric blood and marrow transplants.

SUPERSIBS!

www.supersibs.org

An organization providing support and recognition for brothers and sisters of children and adolescents with cancer, and offering guidance to parents, grandparents, teachers and friends about helping siblings cope.

For more information about resources in your area, refer to the "Information from My Hospital" section of this handbook, or ask your health care team.

**FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG**

Notes and Questions for Your Health Care Team

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After Treatment Ends: What Happens Next?



Most families are eager for the end of their child's cancer treatment, but when the day arrives, they may have mixed feelings. Finishing treatment can be an unsettling time and you may be surprised you are not feeling the joy you thought you would. Worry and anxiety are not uncommon when lifesaving chemotherapy treatment stops. Treatment means action is being taken against the cancer, and ending treatment can arouse fears that cancer may return. Completing treatment also means an end to what has become a familiar routine, an end to the ready access to knowledgeable medical staff, and the beginning of a new, unknown stage of care.

At this time, it is important for you to know that most cancers in children and young people don't come back. We believe that knowledge is power, and we hope that by providing answers to frequently asked questions, you may feel more comfortable entering the next phase of cancer care.

The First Month Off Treatment

After your child's end of treatment date, it may feel odd to stop giving your child medicines that have been fighting the cancer during treatment. It also may feel odd to have follow-up appointments become fewer or farther between. Otherwise, there will be few immediate changes, as it will take several weeks for blood counts to return to normal, and several months for the immune system to recover.

DOES MY CHILD STILL NEED TO TAKE BACTRIM™ (SEPTA®)?

Yes, if your child has been taking Bactrim™ (Septra®), this medicine is usually continued on a 2 to 3 day per week schedule for several months after treatment ends.

WHAT DO I DO IF MY CHILD DEVELOPS A FEVER OR BECOMES ILL?

In the first few weeks after the end of treatment, your child may still have low blood counts and a central line. During this time, you will need to contact the treatment center if your child develops a fever, and your child may need to come to the hospital for antibiotic therapy. Please talk with your health care team about what to do if your child becomes ill.

WHAT HAPPENS IF MY CHILD IS EXPOSED TO CHICKENPOX OR SHINGLES?

You should call the treatment center if your child is exposed to someone with chickenpox or shingles. Your child may need medicine to help prevent infection with the chickenpox virus. If your health care provider has told you that your child had enough of their own immunity against chickenpox during treatment, there is no need to take any action if exposure occurs after treatment ends.

WHEN CAN THE CENTRAL LINE BE REMOVED?

Most children have the central line removed soon after treatment ends. Ask your child's health care team about the right time for your child to have their central line removed. Internal lines (such as a Port-a-Cath® or Medi-Port) are usually taken out in the procedure room or operating room. External lines (such as a Hickman® or Broviac®) are often removed in the clinic. Central line removal is a minor surgical procedure and children generally have minimal discomfort that may last for one or two days following the procedure.

WHAT HAPPENS WHEN A BLOOD TEST IS NEEDED AFTER THE CENTRAL LINE OR PORT IS REMOVED?

Once the central line or port is removed, your child will have blood drawn using a needle. Most children handle venipuncture (blood draw) well, but an occasional child may become distressed by the thought of having a "poke." You can use ice or a local

anesthetic cream or patch, such as EMLA® Cream, to numb the area. Your nurse will help show you where to apply the anesthetic. If blood drawing becomes a problem, the child life specialist may be able to offer your child help coping with the blood tests.

It is important never to be dishonest with your child about an upcoming blood test, as this can lessen their trust in you. At the same time, there is no need to discuss an upcoming blood test weeks before the event. Most child life specialists recommend giving the child a short time to process the information. Your child life specialist can give you other ideas and strategies to help your child better tolerate blood draws.

WHY DOES MY CHILD STILL FEEL TIRED?

When children finish treatment, fatigue is not uncommon. It takes time to rebuild strength and stamina. Most parents find that this can take several months.

HOW OFTEN WILL MY CHILD NEED TO COME BACK TO THE HOSPITAL?

When your child completes treatment, they will be seen often in the clinic. Most children treated for leukemia will need a monthly clinic appointment for a review of the child's progress over the past month, a physical exam and blood counts. Monthly visits generally continue for the first year off treatment. Children treated for a solid tumor may have longer intervals between visits. Your health care team's preference and the policy of your clinic or hospital may be slightly different.

WHAT HAPPENS AT FOLLOW-UP VISITS?

The main purpose of follow-up visits during the first year is to be sure that the cancer has not returned and to start the transition to life after cancer. Children will usually have a complete blood count to assure bone marrow recovery after treatment and also may have blood tests to assess the health of other organs, such as the liver and kidneys. A general check up is done by the health care provider, including questions about how your child is doing, and a physical exam.

Children who were treated for a solid tumor will have scans performed on a regular basis to ensure that they are free of cancer. The frequency of CT scans, MRIs and other tests depends on the type of cancer and treatment plan. You will usually be given a schedule or calendar of the planned follow-up visits and scans at your first follow-up clinic visit.

IS IT OKAY IF I DON'T FEEL LIKE CELEBRATING?

Parents and patients find that friends and family members are often overjoyed for them at the end of treatment. You may be greeted with big smiles and told how well your child looks, and you may be asked, "Isn't it great that your child finished chemo?"

For many families, but not for all, a celebration feels very appropriate. Your child and family have just gotten through the huge challenge of treatment. That is a great achievement. The celebration might be low-key, such as going to the park on what previously would have been a clinic day. Some families choose to have a family party or celebration at school. Some find that planning an enjoyable vacation gives them something positive to focus on. Other parents find that their own reactions are much more cautious, because they are worried about the future. Even if there are a lot of challenges ahead, you and your child have done something pretty amazing by getting through all the weeks, months or even years of treatment. Give yourself a moment to acknowledge this milestone. Whatever you and your child choose to do will be right for you.

Two to Six Months Off Treatment

After a few weeks off treatment, most children have normalized blood counts, and the complications of low platelets, low red blood cells and low white counts are decreased. Immune system recovery is progressing, but not yet back to normal.

WHERE DID EVERYBODY GO?

During active treatment, patients and families regularly see health care professionals and other parents at the hospital. The health care team offers reassurances that your child is doing well, and they are at hand to answer questions or concerns. Other parents can be a comforting source of information. Yet, when treatment is done, you have less contact with these sources of support.

Parents sometimes find that even people who seemed to understand what they were going through during treatment are not available as often. Teens may feel that many of their friends have abandoned them. It can be particularly hard at this time to find people who realize the pressures and fears that accompany the post-treatment phase.

With a little explanation, or perhaps by lending them this handbook, friends and relatives can come to appreciate that you still have concerns and worries, and better understand your feelings. Some parents create a new support system with online parent groups, or keep in touch with other hospital families via email.

WHAT DO I DO IF MY CHILD DEVELOPS A FEVER, OR BECOMES ILL?

Check with your child's health care provider to determine a plan for management of fevers and minor illnesses. Once your child has a normal blood count and the central line or port has been removed, you may be advised to see your family doctor or pediatrician first. He or she can decide if your child needs to go to the hospital.

WHAT HAPPENS IF MY CHILD IS EXPOSED TO CHICKENPOX, SHINGLES OR OTHER CONTAGIOUS DISEASES?

Your child's immunity will be reduced for up to six months after treatment. Children who have undergone a hematopoietic stem cell transplant may have reduced immunity for a longer period of time. If your child previously needed to take extra medicines when they came into contact with chickenpox or shingles, they will still need these medicines during this time.

DOES MY CHILD STILL NEED TO TAKE BACTRIM™ (SEPTA®)?

Your health care team may stop this medicine after your child has been off treatment for 3 to 6 months.

CAN MY CHILD JOIN IN PHYSICAL EDUCATION CLASS AND SWIMMING?

Once your child's central line or port has been removed and the site has healed, there usually are no restrictions on swimming. Exercise is important for health, and unless there are any specific reasons why your child cannot be physically active, daily exercise should be encouraged. Check with your health care team to make sure there are no restrictions on activities.

WILL MY CHILD'S HAIR COME BACK?

Hair loss, also known as alopecia, is a side effect of some chemotherapy medicines and/or radiation. Hair will usually grow back when cancer treatment has ended. The hair may be a slightly different color or texture (curlier, thicker, or thinner) than before cancer treatment. In some cases, when a child receives high doses of radiation, as is used for brain tumor therapy, hair may not regrow within the radiation site. Please talk with your health care team about any questions or concerns you may have.

WHY AM I ANXIOUS ABOUT COMING BACK TO CLINIC?

Coming back to the clinic for checkups can be stressful. Some parents say that they feel increasingly anxious as the day of the appointment gets closer, and then feel much more relaxed afterwards and are able to forget about the disease for awhile. It is good to remember that the chance of a cancer recurrence at any follow-up appointment is very small.

Coming back to the clinic brings other stresses, too. It can be hard to see children who are still receiving treatment. This may bring back difficult memories of your own child's treatment. Returning to the clinic can also mean that parents hear news of children that they knew during treatment. If this news is bad, it is natural that parents can become very fearful for their own child. It is always important to remember that even when children have the same diagnosis, each child's illness is unique. Talking to your health care team about your concerns may be helpful.



WHY AM I STILL AFRAID THE CANCER WILL COME BACK?

Parents often tell us that the end of treatment feels like losing the child's safety net. During treatment families feel that everything possible is being done to beat the disease. Parents sometimes feel that they would prefer their child remain on low dose chemotherapy for life, if it could guarantee that the disease would not return.

If you are struggling with fears about relapse, it can be helpful to remember that:

- Most childhood cancers do not recur
- The chances of relapse decrease the longer your child has been off treatment
- For many children, treatment may still be successful if the disease does return

WHAT ABOUT BROTHERS AND SISTERS?

Like their parents, brothers and sisters of a sick child may continue to have worries about their brother's or sister's health for some time after treatment. Many children will also realize that even though treatment is over, parents are still focusing more on the child who has been ill. Brothers and sisters often need reassurance that they are loved equally. As brothers and sisters get older, they are likely to need more detailed explanations about the illness, as well as reassurance that the risk of cancer is not increased for them.

WHEN WILL LIFE GET BACK TO NORMAL?

Of course, life will never return to exactly the way it was before your child became ill. However, most parents feel that, in time, the family reaches a "new normal." For some parents, returning to work can feel like a huge step. If you have not seen co-workers since before your child was ill, coping with their reactions can be a challenge. Some parents have found it helpful to visit their work place or meet with co-workers before their first official working day, to help them cope with their own and others' reactions in advance.

WHAT ABOUT DISCIPLINE/BEHAVIOR?

A return to usual discipline within the family is part of returning to the "new normal." When a child is ill, it is easy to let family rules slip. However, by insisting on good behavior, parents can send a very positive message to both the child who was sick and their brothers and sisters that the family is getting back to normal routines and expectations. This helps the whole family remember that they have a future after cancer.

WHAT WILL SCHOOL BE LIKE FOR MY CHILD?

Most children with cancer continue attending school during therapy. A classroom discussion or just sharing the news of ending treatment with their close friends is appropriate. Children who missed large amounts of school due to treatment or

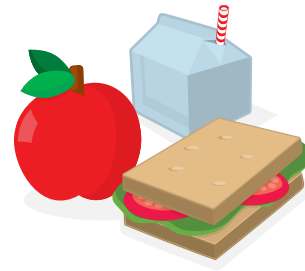


side effects may need time to readjust. Returning to school may cause feelings of anxiety or worry. They may become tearful or express their frustrations in anti-social behavior or temper tantrums. If your child is having these issues, talk with their teacher. You may also want to get help from the school counselor, psychologist or social worker, or a school specialist at the hospital.

Many children find it hard to go back to school, especially if they have changes in their body. Hair loss and weight loss or weight gain are common concerns. Tell your health care team if your child is worried about going back to school. Your child life specialist, social worker, psychologist or nurse may be able to help. If your child is having problems doing school work, ask for extra help. There are two laws in the United States that assist children treated for cancer to receive needed services at school, including an Individualized Education Plan (IEP). These laws are called IDEA (Individuals with Disabilities Education Act) and Section 504 of the Rehabilitation Act. Talk with someone from your health care team to see how these laws, or the laws in your country, may apply to your child.

WHAT ABOUT DIET?

Your child's nutrition and diet may have been affected by cancer treatment. If your child was treated with steroid medicines, they may have developed a craving for salty, unhealthy foods and gained excess weight. Children who received treatment that caused mouth sores, nausea, or diarrhea may have experienced weight loss and developed food aversions (avoiding certain foods). A gradual return to a healthy, normal diet should be the goal. Now is the time to stop high calorie snacking and high sodium foods that may have been eaten during treatment. Your child should be encouraged to eat a variety of foods from all food groups each day. Resist the urge to offer high calorie, empty nutrition foods to children who are underweight. Your clinical dietician is able to help with meal suggestions and menu planning. A healthy diet, including a healthy balance of protein, carbohydrates, fats, vitamins, and minerals is an important part of helping your child's body to grow, heal, and work well. Of course, this is the best way for the whole family to eat!



WHAT ABOUT VITAMIN SUPPLEMENTS AND OVER-THE-COUNTER MEDICINES?

Vitamin supplements are not a replacement for good eating habits. They may be used for children who are unable to tolerate certain food groups, such as milk, or who have low levels of nutrients, such as vitamin D. Some health care providers recommend a daily multivitamin. Check with your health care provider about multivitamin use. Healthy eating and taking supplements when medically needed helps ensure children and

adolescents have a wide range of the nutrients and vitamins needed to remain healthy and function properly.

During the first 6 months after treatment ends, talk with your health care provider before taking:

- Any over-the-counter or other non-prescription medicines
- Herbal medicines

Six to Twelve Months Off Treatment

By this time, most children will have normal blood counts, and by the end of the first year, their immune system has usually returned to normal. Patients who have undergone a hematopoietic stem cell transplant may have a longer period of immune system recovery.

WHAT DO I DO IF MY CHILD DEVELOPS A FEVER, OR BECOMES ILL?

After 6 months off therapy, fevers and minor illnesses generally are handled as they would be for any child. This may mean comfort care like bed rest, acetaminophen (such as Tylenol®), or a visit to the pediatrician if fever is 101° F or more, or if the child appears very ill. It will be hard not to worry when your child has a sore throat or headache even though the most likely cause is a normal childhood illness. For parents of children treated for cancer, minor illness may be very stressful, as it is not easy to keep “normal” childhood illnesses in perspective. It is important to remember that all children get sick at times and recover with rest and comfort care.

ARE THERE ANY CONCERNING SYMPTOMS THAT MAY INDICATE SOMETHING MORE SERIOUS?

Contact your health care provider at your treatment center if your child experiences:

- Prolonged fever over 101° F
- Unexplained bruising
- Repeated headaches and or vomiting in the early morning
- Enlarging lymph glands
- Changes in mental status (confusion, excessive sleepiness)
- Unexplained weakness in the arms or legs
- Changes in bowel or urinary habits
- Unexplained lumps or bumps anywhere on the body

If you have any questions or concerns, please don't hesitate to contact your health care provider. They are there to answer your questions, provide advice, and put your mind at ease.

IS THERE ANYTHING MY CHILD SHOULDN'T DO?

We encourage your child to return to normal activities as soon as they feel able, although some children are left with lasting effects from the cancer or treatment and may not be able to do all they could do before treatment. There may be some activity restrictions based on your child's treatment. For example, some health care providers discourage heavy weight lifting for patients who received high doses of chemotherapy medicines called anthracyclines (such as doxorubicin or daunorubicin). Talk to your health care provider about specific limits for your child.

WHAT ABOUT IMMUNIZATIONS?

Chemotherapy used in conventional doses (not doses used for hematopoietic stem cell transplant) usually does not destroy the immunity gained from immunizations given before the cancer. That means that often there is no need to repeat immunizations that were already given. Your health care provider may test your child to see if any boosters are needed. Many children, especially young children, may have had their routine immunization schedule interrupted during treatment. Most children are able to begin catching up any missed immunizations within 6 to 12 months of the end of treatment. Your health care provider will talk with you about when your child can have immunizations again.

WHO ARE MY BEST SUPPORT SYSTEMS?

Some people find the end of treatment a positive time when they need much less support, but others find this time unsettling. Communication with your partner or spouse (or a trusted supportive person) at this time is essential. The need to talk about feelings, fears, appreciation, and information remains after cancer treatment ends. Silence can make you feel separated from your partner and loved ones. By sharing feelings and information, you can stay connected and be better able to make decisions. Keep in contact with people who have been close to you, and who let you be honest about your feelings. Talking to others can help you to think more clearly. The staff you met during treatment will be aware of the difficulties parents and young people face at the end of treatment. Please talk with them if you feel you need some extra support at this time. Some treatment centers have parent support groups. When these groups are not available, there may be more general cancer support groups in your area. Ask your child's health care team about available support in your area. The organizations listed at the end of this section will also guide you to what counseling services are available in your area. Your primary health care provider may also be able to provide support, advice and guidance.

HOW DO I COPE WHEN I AM REMINDED ABOUT MY CHILD'S DIAGNOSIS OR END-OF-TREATMENT?

Anniversaries of the time of diagnosis or finishing treatment can be very emotional, and for many parents, create feelings of both sadness and joy. In time, many parents find that they can reach a balance between being thankful that their child is free from cancer and the sadness over the inevitable losses the experience has brought. Some families will have to come to terms with many such losses, particularly when children have lasting effects from the cancer treatment.

One Year Off Treatment and Beyond

The “one year off therapy anniversary” is a significant time for many families. Blood counts and immune system have recovered, and hair has returned if it is going to. Children usually have more energy and may be experiencing “catch up” growth. For many children, there is no longer any physical evidence of cancer treatment, but for others the lasting effects of cancer treatment may now be apparent.

WHY DO WE STILL NEED TO COME BACK TO THE CLINIC?

The focus of clinic visits during the second year after treatment ends will be slightly different. The health care team will continue to monitor your child, but the intervals between visits lengthen. Blood tests and scans may be done to be certain that the cancer is gone. The health care team will also concentrate on restoring your child to a state of good health. Talk with your health care provider about your child's specific follow-up plan. After 2 to 5 years, your child's care may be transitioned to the hospital's long-term follow-up clinic.

HOW SHOULD I TALK TO MY CHILD ABOUT THE ILLNESS?

As your child grows up, the amount of information that they need about their illness and its treatment increases. Often, children were too young to remember much about the treatment period. It can be tempting to try to protect your child from the anxiety you feel by not sharing more information about the illness. Children are usually more aware than adults realize. Many children will learn about their illness from comments made by older brothers and sisters, relatives, or friends. Finding out about the illness in this way can mean that they only have part of the story. This may leave them with worries. Fears can be increased if a child cannot talk with a parent about their feelings, concerns, and questions.

It may be hard for your child to ask you about cancer if you never mention it. By talking openly to your child, you are inviting them to share their thoughts about the illness openly too. This will give you a chance to correct any misunderstanding and give your child reassurance. Open communication with a parent allows a child to understand why they still need to come to clinic for appointments even when they are well.

WHY DOES SCHOOL SEEM TO BE HARD FOR MY CHILD?

For some children, intellectual development may be affected by reduced energy levels during treatment and prolonged absences from school. Treatment to manage or prevent disease in the brain may affect memory and learning abilities. Children who had treatment for a brain tumor are more likely to receive treatments that may affect learning and memory. If your child received this type of treatment, let the teacher, principal, and school counselor know.

Some parents and teachers report that children who received therapy to the central nervous system may have difficulty concentrating. The brain is a very complex structure that continues to grow and develop throughout childhood, adolescence, and young adulthood. Neuropsychological testing may help identify learning weaknesses and strengths and help the school give your child extra support so that they can reach their full educational potential.

School difficulties may not appear for years after treatment is completed. Any academic difficulties should be discussed with the health care team, school psychologist or reintegration specialist, and your child's school.

The following can sometimes increase the risk of educational problems:

- A history of learning problems before the diagnosis of cancer
- Frequent or prolonged school absences
- Treatment that has affected hearing or vision
- Treatment that results in physical limitations
- Treatment of the brain and spinal cord – including radiation, certain types of intravenous chemotherapy, and intrathecal chemotherapy (chemotherapy given directly into the spinal column)

HOW DO I HELP MY CHILD MAINTAIN A HEALTHY WEIGHT?

The effects of childhood cancer and treatment on appetite and physical activity are different for each child. The aim is to help your child stay healthy and to perform well in school, play, or at work. Some children have ongoing problems with nutrition and maintaining a healthy weight. Most children will begin to gain weight once treatment is ended, and as a parent, this will be very reassuring. However, some children may gain weight at an unhealthy rate. If your child experiences any weight or nutritional issues please discuss this with your health care team. Meeting with a dietician may also be helpful.

It's a good time to make healthy choices about diet and exercise. A healthy diet and physical activity have many benefits for children who have had treatment for cancer.

These include:

- Helping tissues and organs that have been damaged by the cancer and treatment to heal
- Building your child's strength and energy level
- Reducing the risk of developing certain types of adult cancers and other diseases in adult life
- Reducing the risk of certain long-term complications of cancer treatment
- Reducing feelings of stress and increasing feelings of well-being

A balanced, healthy diet is based on the recommended food groups, which include:

- Bread, whole grains, and cereals
- Fruits
- Vegetables
- Milk and dairy products
- Meat, fish, poultry, and nuts

It is important to combine healthy eating with physical activity. In general, a healthy lifestyle includes not smoking, eating a low fat, high fiber diet, exercising regularly, and avoiding excessive alcohol intake.



DOES MY CHILD NEED SPECIAL PRECAUTIONS WHEN OUTSIDE?

Children and teens should be encouraged to fit some outdoor physical activity into their daily routine. Remember to protect children from sunburn when the skin is exposed to the sun even on cloudy or hazy days.

- Use cover-up clothing and sunscreen with a high SPF (35 or higher)
- Sand, snow, concrete, water, and high altitudes all increase the risk of sun damage, take extra caution to protect your skin in these environments
- Discourage your child from tanning; avoid tanning booths
- Avoid outdoor activities from 10 a.m.–2 p.m. when sun rays are most intense
- Plan outdoor activities in the morning or late afternoon hours
- Re-apply sunscreen every few hours while outside, especially when swimming

WHAT IF MY CHILD HAS HAD A HEMATOPOIETIC STEM CELL TRANSPLANT?

We hope this information helps children who receive treatment for many types of cancer,

as well as their families. However, for children who have received a hematopoietic stem cell transplant, some parts of recovery will be different.

After a hematopoietic stem cell transplant, it can take longer for full immunity to return. This time period is different for each child and will depend on:

- The type of transplant your child has received (for example, if the donor was a family member or an unrelated donor)
- How quickly the new bone marrow starts working
- Whether your child has to take extra medicine to suppress immunity
- Whether your child experiences graft-versus-host disease

Children who have had total body irradiation as part of the preparation for their hematopoietic stem cell transplant also may have some side effects that do not become evident until after treatment has ended.

Because of the intensity of this treatment and the longer recovery period, your child may continue to be cared for by the transplant team for quite some time. The transplant team will be able to tell you when it is safe for your child to return to normal activities, and will also let you know when your child may go back to their primary oncologist or to a long-term follow-up clinic for care.

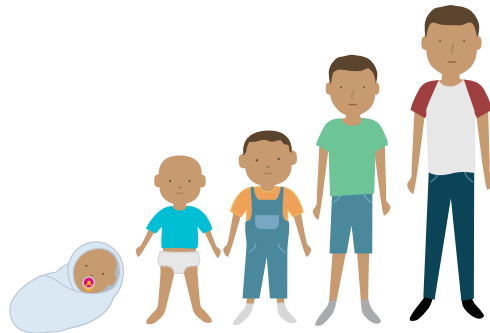
IS FOLLOW-UP FOREVER?

The length of follow-up depends on the treatment received and any lasting effects your child has experienced. The Children's Oncology Group recommends monitoring childhood cancer survivors into adulthood. Recommendations for follow-up are based upon the most current medical knowledge available and are likely to change over time. Testing may include blood work and other procedures. Your health care provider will talk with you about the testing and follow-up your child will need.

WHAT IS TRANSITION?

The process of moving from one situation or place to another is called transition. In childhood cancer, transition means moving from the pediatric oncology team that cared for your child during treatment to a long-term follow-up clinic or primary care provider who will care for them as a survivor of childhood cancer.

Long-term follow-up care varies in each cancer center. At some centers, this may mean moving



to a different health care provider or a different clinic or hospital when off treatment for 2 to 5 years or longer. Other cancer centers continue to provide care for patients indefinitely. Still others have clinics especially for adult survivors of childhood cancer. Your health care provider will discuss any transition your child may have in the future, and help to ensure that any transitions go as smoothly as possible.

You and your health care provider can help your child get ready for a transition by:

- Encouraging your child to learn about their cancer and the treatment they received
- Explaining why follow-up is needed
- Encouraging your child to ask questions

We hope that providing answers to parents' most frequently asked questions was useful. Your health care provider will discuss these issues in greater detail during your clinic visits.

Helpful Organizations After Cancer Treatment Ends

CHILDREN'S ONCOLOGY GROUP

www.childrensoncologygroup.org

Online information regarding cancer in children, adolescents, and young adults, including information about follow-up care, written by experts from the Children's Oncology Group, a network of more than 200 hospitals that form the world's largest pediatric cancer research organization.

CURESEARCH

www.curesearch.org

CureSearch.org is an online resource for patients, their families and support systems. The website provides up-to-date information about the various types of children's cancer along with research trials; definitions and descriptions of tests, procedures, and treatments; and information to help families manage the emotional aspects of caring for a child with cancer.

CHILDREN'S ONCOLOGY GROUP LONG-TERM FOLLOW-UP GUIDELINES

www.survivorshipguidelines.org

Information about staying healthy after childhood cancer and guidelines for long-term follow-up care from Children's Oncology Group experts.

AMERICAN CHILDHOOD CANCER ORGANIZATION

www.acco.org

Founded by parents of children with cancer, the American Childhood Cancer Organization offers information, support, and advocacy for children and adolescents with cancer and for pediatric cancer survivors through local affiliates and at a national level.

FERTILE HOPE

www.fertilehope.org

Fertile Hope provides information about reproductive options to cancer patients and survivors who are at risk for infertility due to cancer treatment.

NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES

www.nichcy.org

A central source of information regarding disabilities in children and youth, including information about special education and laws that protect children's rights.

SURVIVING AND MOVING FORWARD: THE SAMFUND

www.thesamfund.org

Assists young adult cancer survivors (ages 17-35) to achieve their personal and professional goals by providing financial support through distribution of grants and scholarships to help pay for education or other post-treatment transitional expenses.

FOR MORE INFORMATION ABOUT CHILDHOOD CANCER AND ITS TREATMENT, PLEASE VISIT:
WWW.CURESEARCH.ORG + WWW.CHILDRENSONCOLOGYGROUP.ORG

Notes and Questions for Your Health Care Team

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Glossary

Childhood cancer has its own complex vocabulary. This glossary explains the terms that you are likely to come across throughout the stages of cancer. Portions of this glossary have been provided by the National Cancer Institute website, the CureSearch website, and the Teens Living With Cancer website. For definitions not listed here, see cancer.gov/dictionary.

A

ABDOMEN

(AB-doh-men)

The part of your body between the chest and the pelvis containing the stomach (with the lower part of the esophagus), small and large intestines, liver, gallbladder, spleen, pancreas, and bladder.

ABSOLUTE NEUTROPHIL COUNT (ANC)

(AB-suh-loot NOO-tro-fil count)

The percentage of polys and bands that are part of your total white blood count. If your ANC is less than 1,000, you are more prone to infection.

ALOPECIA

(al-oh-PEE-shuh)

Hair loss. This often occurs as a result of chemotherapy or from radiation therapy to the head. In most cases, the hair grows back after treatment ends.

ANEMIA

(uh-NEE-mee-uh)

Low red blood cell count which can cause you to feel fatigued and have shortness of breath. Anemia can be caused by a variety of conditions and diseases.

ANESTHESIOLOGIST

(A-nes-THEE-zee-AH-loh-jist)

A doctor who specializes in giving medicines or other agents to block the sensation of pain and/or allow you to sleep, especially during surgery. *See **sedation and local anesthesia**, page 31.*

ANTIBIOTIC

(AN-tee-by-AH-tik)

Drug used to kill organisms that cause infection. Since some cancer treatments can reduce your body's ability to fight infection, antibiotics may be used to treat or prevent these infections.

ANTIEMETIC

(AN-tee-eh-MEH-tik)

A drug that prevents or relieves nausea and vomiting, common side effects of chemotherapy.

ANTIFUNGAL

(AN-tee-FUN-gul)

A medicine that kills fungi, organisms that cause infections. Kids undergoing treatment for cancer are especially vulnerable to fungal infections.

AUDIOGRAM

(AW-dee-oh-gram)

A diagnostic test that is done to evaluate your hearing.

AUTOLOGOUS HEMATOPOIETIC STEM CELL TRANSPLANT

(aw-TALL-oh-gus hee-MAH-toh-poy-EH-tik stem cell transplant)

When your own stem cells are used for a hematopoietic stem cell transplant. *See **hematopoietic stem cell transplant**, page 58.*

B

BACTERIA

(bak-TEER-ee-uh)

A term for a group of living organisms that may be seen only through a microscope. In general, most are harmless unless the body's resistance is lowered, then they can cause infections.

BANDS

Young, white blood cells; important in defending your body against infection.

BENIGN

(beh-NINE)

Not malignant or cancerous. Benign tumors may grow larger but do not spread to other parts of the body. Also called nonmalignant.

BIOPSY

(BY-op-see)

The removal of a sample of tissue to see whether cancer cells are present and to determine an exact diagnosis. There are several kinds of biopsies.

BLAST CELLS

Refers to the earliest-formed marrow cells. In acute leukemias, blast cells are abnormally formed and accumulate in large numbers.

BLOOD

Blood takes oxygen and nutrients to the tissues, and carries away wastes. Blood is composed of a liquid portion called plasma and three other components: red blood cells, white blood cells and platelets.

BLOOD CHEMISTRIES

A procedure in which a sample of blood is examined to measure the amounts of certain substances made in the body. Blood chemistry tests are helpful in assessing your kidney and liver function.

BLOOD COUNT

A laboratory study to evaluate the number of white blood cells, red blood cells, and platelets in the blood. Also called CBC and complete blood count.

BLOOD TRANSFUSION

(blood tranz-FYOO-zhun)

The infusion of red blood cells or platelets into your blood stream to replace blood loss or to correct anemia.

BLOOD TYPING AND CROSS MATCHING

Making sure that the blood from a donor is compatible with yours before a blood transfusion. Blood cells contain factors that are not the same in all people. Before a transfusion can be given, blood samples from the donor and you are typed, or classified according to which of these factors are present. The four principal red blood cell types or groups are A, B, AB or O. Other factors such as Rh factor must also be checked.

BONE MARROW

(bone MAYR-oh)

The spongy material that fills the cavities of the bones and is the substance in which blood cells are produced. In order to determine the condition of the bone marrow, a health care provider may take a small sample from one of the bones in the hip. *See bone marrow aspiration and biopsy, pages 32-34.*

BONE MARROW ASPIRATION AND BIOPSY

(bone MAYR-oh AS-pih-RAY-shun and BY-op-see)

A procedure in which a needle is placed into the cavity of a bone, usually the hip bone, to remove a small amount of bone marrow for examination under a microscope.

BONE MARROW TRANSPLANT (BMT)

See hematopoietic stem cell transplant (HSCT), page 58.

BONE SCAN

An imaging method that gives important information about the bones, including the location of cancer that may have spread to the bones. A low-dose radioactive substance is injected into a vein and pictures are taken to see where the radioactivity collects, pointing to an abnormality.

BOWEL

(BOW-ul)

The long, tube-shaped organ in the abdomen that completes the process of digestion. The bowel has two parts, the small bowel and the large bowel. Also called intestine.

C

CANCER

(KAN-ser)

Develops when cells in your body begin to grow out of control. Normal cells grow, divide, and die naturally. Instead of dying, cancer cells continue to grow and form new abnormal cells. Cancer cells often travel to other body parts where they grow and replace normal tissue. This process is called metastasis. Cancer cells develop because of damage to DNA. DNA is in every cell and directs all its activities. When DNA becomes damaged, the body is usually able to repair it. In cancer cells, the damage is not repaired. People can inherit damaged DNA, which accounts for inherited cancers. Many times, DNA becomes damaged by exposure to something in the environment, like smoking. Most childhood cancers have no known cause. Also called malignancy.

CATHETER

(KA-theh-ter)

A thin, flexible tube through which fluids enter or leave the body; e.g., a tube to drain urine.

CELL

The basic unit of which all living things are made. Cells replace themselves by splitting and forming new cells (mitosis). The processes that control the formation of new cells and the death of old cells are disrupted in cancer.

CENTRAL NERVOUS SYSTEM (CNS)

(SEN-trul NER-vus SIS-tem)

Refers to the brain and spinal cord.

CENTRAL VENOUS LINE

(SEN-trul VEE-nus line)

A method of giving I.V. fluids, blood products and medicines by surgically inserting a catheter into a large vein (usually in the neck) that passes into your other large blood vessels. There are many different types of central line catheters that may have multiple ports or lumens. Multiple ports allow more than one I.V. solution to be given simultaneously. Blood can also be withdrawn from this type of catheter.

CHEMOTHERAPY

(KEE-moh-THAYR-uh-pee)

Using chemical agents or drugs to destroy cancerous cells. Chemotherapy is often used with surgery or radiation to treat cancer. Some chemotherapy treatment plans have different phases: Induction-intensive treatment used to produce a complete remission. Maintenance - drugs given after the initial Induction to maintain the remission.

CHRONIC

(KRAH-nik)

A disease process that develops over a long period of time and progresses slowly.

CLINICAL

(KLIH-nih-kul)

In general, pertaining to observation and treatment of patients.

CLINICAL TRIALS

(KLIH-nih-kul TRY-uls)

Research studies done to help us understand more about diseases, such as why they happen and how to best treat them.

COLON

(KOH-lun)

The large intestine.

COMPLEMENTARY THERAPY

(KOM-pleh-MEN-tuh-ree THAYR-uh-pee)

Therapies used in addition to conventional therapy. Some complementary therapies may help relieve certain symptoms of cancer, relieve side effects of conventional cancer therapy, or improve a patient's sense of well-being. However, certain complementary therapies must be used with caution because they may interact with chemotherapy, making it less effective.

COMPLETE BLOOD COUNT (CBC)

An examination of your blood that enables health care providers to follow the course of your disease and to select the proper dosage of the appropriate chemotherapeutic drug. White blood count (WBC) refers to the number of white blood cells (leucocytes) per cubic millimeter present in your blood. "Diff" (differential count) refers to the distribution of the various types of white cells in the blood; the values are expressed in percentages. Platelet count refers to the number of platelets per cubic millimeter present in your blood. Hemoglobin refers to the substance that carries oxygen to other tissues of the body. It is expressed as weight per unit of blood volume. Hematocrit refers to the percentage of red cells in whole blood.

CONSTIPATION

(KAHN-stih-PAY-shun)

A condition in which stool becomes hard, dry, and difficult to pass, and bowel movements don't happen very often. Other symptoms may include painful bowel movements, and feeling bloated, uncomfortable, and sluggish.

CONSULTATION

(konsul-TAY-shun)

The formal process of getting the opinion of a specialist.

CONTAGIOUS

(kon-TAY-jus)

A disease capable of being spread from one person to another. Cancer is not contagious.

CONVULSION

(kon-VUL-shun)

A sudden contraction and spasm of your muscles over which you have no control. Convulsions are often accompanied by loss of consciousness (fainting). Also called seizure.

CT SCAN

A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called CAT scan, computed tomography scan, computerized axial tomography scan, and computerized tomography.

CULTURE

(KUL-cher)

A procedure using a sample of blood, urine, throat secretions or other biological material that determines the specific organism responsible for an infection. Cultures also help determine which antibiotics might be most effective.

CYTOGENETICS

(SY-toh-jeh-NEH-tix)

The process of analyzing the number and shape of cell chromosomes.

D

DEHYDRATION

(dee-hy-DRAY-shun)

A condition caused by the loss of too much water from the body. Severe diarrhea or vomiting can cause dehydration.

DIAGNOSIS

(DY-ug-NOH-sis)

Identifying a disease by its signs or symptoms, and by using imaging procedures and laboratory findings.

DIARRHEA

(dy-uh-REE-uh)

Frequent, loose and watery stools.

DIFFERENTIAL COUNT

(diff-fur-REN-shul count)

Refers to the distribution of the various types of white cells in the blood. Also called "diff." *See complete blood count, page 37.*

E

ECHOCARDIOGRAM

(EH-koh-KAR-dee-AH-gram)

A method of obtaining a graphic picture of the structure, position, and motion of your heart through the use of sound waves directed through your chest.

ELECTROCARDIOGRAM(ECG OR EKG)

(ee-LEK-troh-KAR-dee-oh-gram)

A method of evaluating your heart rhythm and muscle function by the measurement of your heart's electrical impulses.

ELECTROLYTES

(ee-LEK-troh-lites)

A general term for the many minerals necessary to provide the proper environment for the cells of your body. Common electrolytes include calcium, sodium, potassium and chloride. Blood chemistries usually include electrolytes.

ERYTHROCYTE

(eh-RITH-roh-site)

Another name for red blood cell. Erythrocytes carry oxygen to the cells throughout your body.

F

FEBRILE

(FEH-brile)

Fever, elevated body temperature.

FELLOW

A physician who has completed residency training. May be a fully trained pediatrician or internist and is doing further study to become a sub-specialist in a field of interest.

FUNGI

A group of microorganisms that occasionally cause serious infection when your resistance is lowered.

G

GENERAL ANESTHETIC

(general A-nes-THEH-tik)

A medication that prevents pain by allowing you to sleep during an operation.

GLAND

An organ that makes one or more substances, such as hormones, digestive juices, sweat, tears, saliva, or milk. Endocrine glands release the substances directly into the bloodstream. Exocrine glands release the substances into a duct or opening to the inside or outside of the body.

GRAFT VERSUS HOST DISEASE (GVH OR GVHD)

The condition that results when the immune cells of a transplant (usually of hematopoietic stem cells) from a donor attack the tissues of the person receiving the transplant.

GRANULOCYTE-COLONY STIMULATING FACTOR (G-CSF)

(GRAN-yoo-loh-SITE-KAH-luh-nee-STIM-yoo-LAY-ting FAK-ter)

Type of growth factor that stimulates production of cells in the bone marrow that produce infection-fighting white blood cells (known as neutrophils or granulocytes). G-CSF is naturally produced in the body, but extra amounts may be given by injection to reduce or prevent low levels of infection-fighting white blood cells (neutropenia) after chemotherapy. *See growth factor, below.*

GROWTH FACTOR

(grothe FAK-ter)

A naturally occurring protein that causes cells to grow and divide. Too much growth factor production by some cancer cells helps them grow quickly. Other growth factors help normal cells recover from side effects of chemotherapy. Some growth factors are also produced in the laboratory and used during cancer treatment. *See granulocyte-colony stimulating factors, above.*

H

HEMATOCRIT

(hee-MAT-oh-krit)

The percentage of the blood composed of red blood cells.

HEMATOLOGIST

(HEE-muh-TAH-loh-jist)

A doctor who specializes in diseases of the blood and blood-forming tissues.

HEMATOLOGY

(HEE-muh-TAH-loh-jee)

The study of blood and blood forming organs.

HEMATOLOGY/ONCOLOGY(HEM/ONC)

(HEE-muh-TAH-loh-jee/ on-KAH-loh-jee)

The branch of medical science that treats disorders of the blood, blood forming tissues and cancer.

HEMATOPOIETIC STEM CELL TRANSPLANT (HSCT)

(hee-MAH-toh-poy-EH-tik stem cell transplant)

A very rigorous treatment for cancer in which high doses of chemotherapy and/or radiation are given to destroy cancer cells. The treatment also destroys the remaining bone marrow, thus new bone marrow or hematopoietic stem cells are given back so that the immune system can regenerate. In allogeneic transplantation, stem cells from another individual, usually a brother or sister with the same tissue type is given to the patient. These stem cells will become the patient's new bone marrow and will eventually begin producing blood cells. In autologous hematopoietic stem cell transplantation, some of your own stem cells or bone marrow is removed and set aside before treatment and then re-infused. The re-infused stem cells start producing blood cells a few weeks later. In umbilical cord blood transplantation, stem cells in blood removed from the umbilical cords of newborns (a very rich source) are used for transplantation.

HEMOGLOBIN

(HEE-moh-GLOH-bin)

The substance in red cells that carries oxygen.

HODGKIN LYMPHOMA

(HOJ-kin lim-FOH-muh)

A type of cancer that affects the lymphatic system and arises in a lymph node. Named after the doctor who first identified it.

HYDRATION

(hy-DRAY-shun)

Defines your condition with regard to body water; may be dehydrated, well hydrated, or excessively hydrated (edematous).

HYPERALIMENTATION

(HY-per-AL-ih-men-TAY-shun)

Being fed intravenously, supplying all the essential nutrients, minerals and vitamins, when you are unable to eat on your own. Also called parenteral nutrition, total parenteral nutrition, and TPN.

I

IMMUNE SYSTEM

(ih-MYOON SIS-tem)

The complex system by which your body resists infection by microbes such as bacteria or viruses and rejects transplanted tissues or organs. The immune system may also help the body fight some cancers.

IMMUNITY

(ih-MYOO-nih-tee)

The state of your body's defenses against a particular infection or possibly against a certain cancer.

IMMUNIZATIONS

(IH-myoo-nih-ZAY-shuns)

Vaccines given to help your body resist disease.

IMMUNOSUPPRESSION

(IH-myoo-noh-suh-PREH-shun)

A state in which your immune system does not respond adequately. This condition may be present at birth, or it may be caused by certain infections (such as human immunodeficiency virus or HIV), or by certain cancer therapies, such as cancer-cell killing (cytotoxic) drugs, radiation, and hematopoietic stem cell transplantation.

IMMUNOTHERAPY

(IH-myoo-noh-THAYR-uh-pee)

Treatments that promote or support your immune system's response to a disease such as cancer.

IMPLANTABLE PORT

An implanted venous access device that provides a system for delivery of fluids, medicines, or blood directly into a vein. The entire device is surgically implanted under the skin and can be used for an extended period of time. Examples include PORT-A-CATH and Mediport.

INCUBATION PERIOD

(in-ku-BAY-shun period)

The period between exposure to a germ and the first sign of illness.

INFECTION(IN-FEK-SHUN)

Invasion of the body by disease-producing organisms (germs). The germs may be bacteria, viruses, yeast, or fungi. They can cause a fever and other problems, depending on where the infection occurs. When the body's natural defense system is strong, it can often fight the germs and prevent infection. Some cancer treatments can weaken the natural defense system.

INFORMED CONSENT

(in-FORMMD kun-SENT)

A process in which a person is given important facts about a medical procedure or treatment, a clinical trial, or genetic testing before deciding whether or not to participate. It also includes informing the patient when there is new information that may affect his or her decision to continue. Informed consent includes information about the possible risks, benefits, and limits of the procedure, treatment, trial, or genetic testing.

INFUSION

(in-FYOO-zhun)

The introduction of fluids into a vein. Also called intravenous infusion.

INJECTION

(in-JEK-shun)

Medication given through a needle. Injections may be given intramuscularly (into a muscle), intravenously (into a vein), subcutaneously (just under the skin) or intrathecally (into the spinal column space).

INTRATHECAL (IT)

(IN-truh-THEE-kul)

Describes the fluid-filled space between the thin layers of tissue that cover the brain and spinal cord. Medicine can be injected into the fluid or a sample of the fluid can be removed for testing. Chemotherapy given intrathecally can kill cancer cells throughout the brain and spinal cord.

INTRAVENOUS (I.V.)

(IN-truh-VEE-nus)

The administration of a drug or fluid directly into the vein.

INVESTIGATIONAL DRUGS

(in-VES-tih-GAY-shuh-nul drugs)

Drugs being studied by clinical investigation to determine the value of these drugs as treatment for certain types of cancer.

J

K

KIDNEY

(KID-nee)

One of a pair of organs in the abdomen, involved in the filtration of certain bodily wastes and in the maintenance of proper mineral and water balance.

L

LEUKEMIA

(loo-KEE-mee-uh)

Cancer that starts in the blood-forming tissue such as the bone marrow and causes large numbers of abnormal blood cells to be produced and enter the bloodstream.

LEUKOCYTOSIS

(loo-ko-sigh-TOE-sis)

Having more than the usual number of white blood cells.

LIVER

An organ in your body which performs many complex functions necessary for life. These include processes related to digestion, production of certain proteins, and elimination of many of the body's waste products.

LOCAL ANESTHETIC

(local A-nes-THEH-tik)

A medication given to prevent pain in a localized area of the body. Local anesthetics do not cause you to become sleepy.

LUMBAR PUNCTURE (LP)

(LUM-bar PUNK-cher)

A procedure in which a thin needle is placed in your spinal canal to withdraw a small amount of spinal fluid or to give medicine into the central nervous system through the spinal fluid. If you have leukemia, a brain tumor, or certain other cancers that arise near the brain or spinal cord, this fluid may be tested for the possible presence of cancer cells. Also called spinal tap.

LYMPH

(limf)

Clear fluid that flows through the lymphatic vessels and contains cells known as lymphocytes. These cells are important in fighting infections and may also have a role in fighting cancer. Also called lymphatic fluid.

LYMPH NODES

(limf nodes)

A part of your body important in the defense against infections. Lymph nodes filter lymph (lymphatic fluid), and store lymphocytes (white blood cells). They are located along lymphatic vessels. In certain types of cancer, lymph nodes enlarge when filled with cancer cells. Also called lymph glands.

LYMPHATIC SYSTEM

(lim-FA-tik SIS-tem)

The tissues and organs (including lymph nodes, spleen, thymus, and bone marrow) that produce and store lymphocytes (cells that fight infection) and the channels that carry the lymph fluid. The entire lymphatic system is an important part of your body's immune system. Invasive cancers sometimes penetrate your lymphatic vessels (channels) and spread (metastasize) to your lymph nodes.

LYMPHOCYTE

(LIM-foh-site)

A type of white blood cell important in immunity and fighting infection. The two main types of lymphocytes are B lymphocytes and T lymphocytes. B lymphocytes make antibodies, and T lymphocytes help kill tumor cells and help control immune responses.

LYMPHOMA

(lim-FOH-muh)

Cancer of the lymphatic system, a network of thin vessels and nodes throughout the body. The two main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma. The treatment methods for these two types of lymphomas are very different.

M

MAGNETIC RESONANCE IMAGING (MRI)

(mag-NEH-tik REH-zuh-nunts IH-muh-jing)

A method of taking pictures of the inside of the body. Instead of using x-rays, MRI uses a powerful magnet and transmits radio waves through the body; the images appear on a computer screen as well as on film. Like x-rays, the procedure is physically painless, but some people may find it psychologically uncomfortable to be inside the MRI machine.

MALIGNANT TUMOR

(muh-lig-nant TOO-mer)

A mass of cancer cells that may invade surrounding tissues or spread (metastasize) to distant areas of your body.

METASTASIS

(meh-TAS-tuh-sis)

The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

MONITOR

(MAH-nih-ter)

To regularly watch and check a person's condition to see if there is any change. Also refers to a device that records and/or displays patient data, such as heart activity or breathing.

MONOCLONAL ANTIBODIES

(MAH-noh-KLOH-nul AN-tee-BAH-dees)

Antibodies made in the laboratory and designed to target specific substances called antigens. Monoclonal antibodies that are attached to chemotherapy drugs or radioactive substances are being studied to see if they can seek out antigens unique to cancer cells and deliver these treatments directly to the cancer, thus killing the cancer cells without harming healthy tissue. Monoclonal antibodies are also used in other ways, for example, to help find and classify cancer cells.

MONOCYTE

(MAH-noh-site)

A type of young white blood cell.

MRI

See Magnetic Resonance Imaging, page 36.

MUCOSITIS

(Mew-koh-SIGH-tis)

Inflammation of the mucous membrane, such as the surface of the inside of the mouth.

MYELOSUPPRESSION

(MY-loh-suh-PREH-shun)

A reduction in platelets, red cells and white cells, as a result of decreased bone marrow activity. Platelets are the blood cells that prevent or stop bleeding. Red blood cells carry oxygen around the body. White blood cells help prevent infections.

N

NAUSEA

(NAW-zee-ah)

The feeling that you may vomit. Nausea is a side effect of some types of cancer therapy.

NEOPLASM

(NEE-oh-PLA-zum)

An abnormal growth (tumor) that starts from a single altered cell; a neoplasm may be benign (not cancer) or malignant. Cancer is a malignant neoplasm.

NEPHROLOGIST

(neh-FRAH-loh-jist)

A doctor who specializes in diseases of the kidneys.

NEUROLOGY

(nur-AH-loh-jee)

The branch of medical science which deals with the nervous system.

NEUROSURGEON

(NUR-oh-SER-jun)

A doctor specializing in operations to treat nervous system disorders.

NEUTROPENIA

(new-troh-PEE-nee-uh)

Less than the normal number of neutrophils (infection-fighting white blood cells) in the circulating blood.

NEUTROPHILS

(NEW-troh-fils)

White blood cells that fight bacterial infection. Also known as granulocytes, polys or segs.

NON-HODGKIN LYMPHOMA

(non-HOJ-kin lim-FOH-muh)

A type of cancer of the lymphatic system.

NUCLEAR MEDICINE SCAN

(NEW-kee-er MEH-dih-sin SKAN)

A method for localizing diseases of internal organs such as the brain, liver, or bone by injecting small amounts of a radioactive substance (isotope) into the bloodstream. The isotope collects in certain organs and a special camera is used to produce an image of the organ and detect areas of disease.

NURSE PRACTITIONER

(Nurse prak-TIH-shuh-ner)

A registered nurse who has additional education and training in how to diagnose and manage illness; usually works closely with a doctor. Also called advanced practice nurse, APN, and NP.



ONCOLOGIST

(on-KAH-loh-jist)

A doctor with special training in the diagnosis and treatment of cancer. A pediatric oncologist is a doctor who specializes in children's cancers.

ONCOLOGY

(on-KAH-loh-jee)

The branch of medicine concerned with the diagnosis and treatment of cancer.

OPHTHALMOLOGIST

(OF-thul-MOL-oh-jist)

A medical doctor who specializes in diseases of the eye.

ORGAN

Several tissues grouped together to perform one or more functions in the body.

ORTHOPEDIC SURGEON

(or-tho-pee-dik SER-jun)

A surgeon who specializes in diseases and injuries of the bones.

P

PATHOLOGY

(puh-THAH-loh-jee)

The branch of medicine involved in making diagnoses from the examination of tissues.

PERIPHERAL

(peh-RIH-feh-rul)

Near the surface; distant. Peripheral nerves are those in your arms and legs; peripheral veins are those generally used for I.V.'s.

PETECHIAE

(peh-TEH-kee-a)

Tiny localized hemorrhages from the small blood vessels just beneath the surface of the skin. They are often the result of platelet deficiency and always clear up completely when your platelet count rises.

PHARMACOLOGY

(FAR-muh-KAH-loh-jee)

The study of drugs, their absorption, distribution and excretion throughout the body.

PHERESIS

(fer-E-sis)

A special method of collecting blood when only one component of the blood is needed. Also known as apheresis.

PHYSICIAN ASSISTANT

(fih-ZIH-shun uh-SIS-tunt)

A person who is trained to assist the physician in coordinating and providing medical care.

PLASMA

(PLAZ-muh)

The liquid portion of the blood in which blood cells are suspended. It contains many proteins and minerals necessary for normal body functioning.

PLATELET

(PLATE-let)

A part of the blood that plugs up holes in blood vessels after an injury. Chemotherapy can cause a drop in the platelet count, a condition called thrombocytopenia that carries a risk of excessive bleeding.

PLEURAL EFFUSION

(PLOOR-ul eh-FYOO-zhun)

The presence of fluid in the space between the lung and the chest wall.

PNEUMONIA

(noo-MOH-nyuh)

Infection of the lung.

POLYS

The group of white cells that is important to your ability to resist bacterial infection. A poly count of less than 1,000 indicates less than normal protection and considerable risk of infection. Also known as neutrophils or granulocytes.

POST-OP

After surgery.

POTASSIUM

(po-TASS-ee-um)

An element found normally in your blood; important in heart and muscle function.

PRE-OP

Before surgery.

PROGNOSIS

(prog-NO-sis)

A prediction of the course of disease; the likelihood of a cure. A prognosis is based on the average result in many cases, and consequently, may not accurately predict your outcome, since the clinical course can vary greatly from patient to patient.

PROPHYLACTIC

(PROH-fih-LAK-tik)

Treatment designed to prevent a disease or a complication that has not yet become evident.

PROSTHESIS

(pros-THEE-sis)

An artificial device to replace a part of your body, such as an artificial knee joint.

PROTOCOL

(PROH-toh-kol)

A formal outline or plan of therapy, such as a description of what treatments you will receive and exactly when each should be given.

PULMONARY

(PUL-muh-NAYR-ee)

Pertaining to your lungs.

PULMONARY FUNCTION TEST

(PUL-muh-NAYR-ee FUNK-shun test)

Special tests that are designed to evaluate the function of your lungs. Also called PFT.

Q

R

RADIATION ONCOLOGIST

(RAY-dee-AY-shun on-KAH-loh-jist)

A doctor who specializes in using radiation to treat cancer.

RADIATION THERAPY

(RAY-dee-AY-shun THAYR-uh-pee)

Treatment with high-energy x-rays to kill cancer cells or shrink tumors. The radiation may come from outside of the body (external radiation) or from radioactive materials placed directly in the tumor (internal or implant radiation). Radiation therapy may be used to reduce the size of a cancer before surgery, to destroy any remaining cancer cells after surgery, or, in some cases, may be the main treatment.

RECTUM

(REK-tum)

The last several inches of the large intestine.

RED BLOOD CELLS

Blood cells that carry oxygen to the cells throughout your body. Also called erythrocyte and RBC.

RELAPSE

(REE-laps)

Reappearance of cancer after a disease-free period.

REMISSION

(ree-MIH-shun)

Complete or partial disappearance of the signs and symptoms of cancer in response to treatment; the period during which a disease is under control. A remission may not be a cure.

RENAL

(REE-nul)

Pertaining to your kidneys.

RESIDENT

A physician receiving additional training after completing medical school.

RESISTANCE

Your ability to fight off and avoid disease.

RETICULOCYTE COUNT

(reh-TIK-yoo-loh-site count)

Refers to the percentage of young, non-nucleated erythrocytes (red blood cells) present in the blood.

S

SARCOMA

(sar-KOH-muh)

A cancer of cells that would normally become connective tissue, such as bone, cartilage, fat, muscle, nerve sheath, blood vessels, and joint lining.

SCAN

A study using either x-rays or radioactive isotopes to produce images of internal body organs.

SEDATIVE

(SEH-duh-tiv)

A drug given to make you drowsy or sleepy.

SEG

A type of white blood cell essential to defend your body against infection.

SEPTICEMIA

(sep-tih-SEE-mee-ah)

A very serious bacterial or fungal blood infection. It is usually associated with high fever, shaking chills, and heavy sweating. It is more likely to occur in patients with very low white blood cells. Also called sepsis.

SHINGLES

A viral infection of the nerve endings in the skin with blisters, crusts and severe pain along the course of the involved nerve. It is the same virus that causes chickenpox. Children who have not had chickenpox may develop chickenpox after contact with someone with shingles. Also called herpes zoster.

SIBLING

A brother or sister.

SIMULATION

A procedure required for planning radiation therapy that involves taking measurements and x-rays to determine radiation treatment fields.

SPINAL CORD

(SPY-nul kord)

The nerve tissue that runs through the center of your spinal column connecting your brain to other parts of your body.

SPINAL TAP

(SPY-nul tap)

A procedure in which a thin needle is placed in your spinal canal to withdraw a small amount of spinal fluid or to give medicine into the central nervous system through the spinal fluid. If you have certain kinds of cancer, this fluid is tested for the possible presence of cancer cells. Also called lumbar puncture.

SPLEEN

An organ that filters the blood, removing debris, and old or dying cells from the circulation. It also removes bacteria from the blood during the early stages of severe infections. It frequently becomes enlarged in leukemia, lymphoma, and certain other diseases.

STAGING

(STAY-jing)

The process of finding out whether your cancer has spread and if so, how far. It is important to know the stage of the disease in order to plan the best treatment.

STEM CELLS

Primitive cells in the bone marrow that are important in making red cells, white cells, and platelets.

STOMATITIS

(STOW-mah-tie-tis)

Mouth sores; can be a side effect of some kinds of chemotherapy.

SUPPOSITORY

(suh-POZ-ih-TOR-ee)

A form of medicine that melts at body temperature. A suppository is inserted into the rectum, vagina, or urethra, where it is generally absorbed into the bloodstream.

SYMPTOM

A change or sign in the body or its function which indicates disease or infection. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.

T

TEMPERATURE SPIKE

When your temperature suddenly becomes elevated or goes up.

THROMBOCYTOPENIA

(THROM-boh-sy-toh-PEE-nee-uh)

A decrease in the number of platelets in your blood; can be a side effect of chemotherapy. Thrombocytopenia may result in easy bruising and excessive bleeding.

TISSUE

(TISH-oo)

A collection of cells similar in structure and function.

TOXICITY

(tok-SIS-it-tee)

A word used to describe the undesirable side effects caused by a medical treatment.

TRANSFUSION REACTION

(tranz-FYOO-zhun reaction)

An allergic response to blood products. You may experience hives, chills or headaches.

TUMOR

(TOO-mer)

An abnormal lump or mass of tissue. Tumors can be benign (not cancerous) or malignant (cancerous). Also called neoplasm.

U

ULTRASOUND

(UL-truh-SOWND)

An imaging method in which high-frequency sound waves are used to outline a part of your body. The procedure can be done to any part of the body—the presence, progression or regression of a tumor or infection can be monitored this way. Also called ultrasonography.

UNILATERAL

(YOO-nih-LA-teh-rul)

One side of your body.

URIC ACID

(YUR-ik A-sid)

A chemical which sometimes accumulates in your body when kidney function is impaired. When many cancer cells are rapidly destroyed, uric acid may be produced in large quantities.

URINALYSIS

(YOOR-in-AL-ih-siss)

A test that determines the content of the urine.

URINARY TRACT

(YOOR-in-air-ee trak)

The organs that have to do with the production and elimination of urine. These include the kidneys, bladder, ureters, and urethra.

V

VARICELLA

(var-eh-SEL-lah)

Chickenpox, an infection caused by a virus. Children with cancer who have never had chickenpox may develop a more severe form of this infection.

VEIN

(vayn)

A blood vessel carrying blood from the tissues towards your heart and lungs. Veins are used to draw blood samples and administer I.V. fluids because blood in veins is not under high pressure.

VIRUS

(VY-rus)

Microorganism that can cause infections. Examples include measles, mumps, chickenpox, and the common cold.

VOMIT

(VAH-mit)

To eject the contents of your stomach through your mouth.

W

WHITE BLOOD CELLS

Cells in your blood that are most important in fighting infection. Examples include granulocytes, monocytes and lymphocytes. Also called leukocyte and WBC.

X

X-RAYS

One form of radiation that can be used at low levels to produce an image of the body on film or at high levels to destroy cancer cells.

Y

Z

ZOSTER

See shingles, page 149.

*CureSearch for
Children's Cancer*

and

*The Children's
Oncology Group*

The Children's Oncology Group (COG), a National Cancer Institute-supported cooperative clinical trials group, is the world's largest organization devoted exclusively to childhood and adolescent cancer research. The COG conducts bench-to-bedside research by developing new treatments and conducting clinical trials that translate scientific discoveries into cures.

With over 200 member hospitals worldwide and over 7,000 physicians, nurses and other researchers, Children's Oncology Group hospitals provide the unmatched combination of global expertise and local care. This means that every child and care team has complete access to the latest research and world-class treatments at hospitals close to home.

WHY IS COLLABORATIVE RESEARCH IMPORTANT?

While nearly 13,500 children and adolescents are diagnosed with cancer each year in the United States, there are many different kinds of children's cancer. The number of children with each type of cancer is relatively small. Including adequate numbers of patients in research studies is necessary to ensure that study results are meaningful. This can usually only happen by enrolling patients from many hospitals in the same trial. This approach is called collaborative research and is how the Children's Oncology Group functions.

HOW MANY COG TRIALS ARE OPEN AND WHAT TYPES OF TRIALS ARE THERE?

The Children's Oncology Group has nearly 100 active clinical trials open at any given time. These trials include front-line treatment for many types of childhood cancers, studies aimed at determining the underlying biology of these diseases, and trials involving new and emerging treatments, supportive care, and survivorship.

ONLY RESEARCH CURES CHILDREN'S CANCER

Through collaborative research, the Children's Oncology Group has improved cure rates for children's cancer at a pace much faster than any one individual or single institution could accomplish alone. Children's Oncology Group research has turned children's cancer from a virtually incurable disease 50 years ago to one with a combined 5-year survival rate of 80% today. Our goal is to cure all children and adolescents with cancer, reduce the short and long-term complications of cancer treatments, and determine the causes and find ways to prevent childhood cancer.

CureSearch for Children's Cancer

VISION

To guarantee a cure for every child with cancer through research.

MISSION

To fund and support children's cancer research and to provide information and resources to all those affected by children's cancer.

CureSearch for Children's Cancer is a non-profit foundation whose mission is to fund and support children's cancer research and provide information and resources to all those affected by children's cancer. CureSearch raises funds for promising research conducted at more than 175 hospitals in the United States. These hospitals participate in National Cancer Institute sponsored clinical trials conducted by the Children's Oncology Group. CureSearch also funds other clinical, basic, and translational research so that researchers can understand all aspects of children's cancer, from its causes to its consequences. To support this work, CureSearch raises funds through individuals, special events, corporations, and private foundations.

CureSearch also manages the operations center of the Children's Oncology Group, the largest cooperative research entity in the world. With more than 7,000 physicians, nurses and other researchers, COG member hospitals treat 90% of children in the United States with cancer.

In the last 50 years, the combined 5-year survival rate for children's cancer has increased from 10% to 80%. At CureSearch, our goal is 100%.

CHILDREN AND ADOLESCENTS WITH CANCER

- Every day, 36 children are diagnosed with cancer.
- Children's cancer affects all ethnic, gender and socio-economic groups.
- The average age of children diagnosed is six.
- More than 40,000 children undergo treatment for cancer each year.

RESOURCES FOR PATIENTS AND FAMILIES

In addition to funding clinical research, CureSearch for Children's Cancer also supports patients and families by providing tools designed to help them through the cancer experience.

CureSearch.org is an online resource for patients, their families, and support systems. The website provides up-to-date information about the various types of children's cancer along with research trials; definitions and descriptions of tests, procedures, and treatments; and information to help families manage the emotional aspects of caring for a child with cancer.

The Family Handbook is distributed to families via Children's Oncology Group hospitals. It is a three-ring binder with information to guide parents through all of the stages of their child's cancer, from diagnosis to treatment and into survivorship.

The Hope and Help Journal is a spiral-bound notebook given to parents when their child is diagnosed and is designed as a place for parents to write and track questions and details related their child's treatment. The *Journal* also contains a list of questions to ask when parents first learn their child has cancer.

BE PART OF THE CURE

To reach our goal of 100% cure rate for children with cancer, CureSearch is mobilizing individuals, families, and corporations across the nation to join our efforts. CureSearch has Regional Offices throughout the country that organize events and activities to raise funds for research on behalf of children living with cancer.

There are many ways you can help fight children's cancer, such as joining the CureSearch Walk or one of our many other events, starting your own event or joining your local Fundraising Council. Please contact us at 800-458-6223 or online at www.curesearch.org if you would like to partner with CureSearch for Children's Cancer.

