Childhood Leukemia Overview

What is childhood leukemia?

Leukemia is a type of cancer that starts in early forms of blood cells. Cancer starts when cells grow out of control. Cells in nearly any part of the body can become cancer. To learn more about how cancers start and spread, see *What Is Cancer?* For information about the differences between childhood cancers and adult cancers, see *Cancer in Children*.

Most of the time, leukemia is a cancer of the white blood cells, but some leukemias start in other kinds of blood cells. Leukemia starts in the bone marrow, the soft inner part of certain bones where new blood cells are made, and quickly spreads to the blood. From there it can go to other parts of the body.

Some other types of childhood cancer, such as Wilms tumor (a kidney cancer), can start in other organs and then spread to the bone marrow (or elsewhere). But those cancers are *not* leukemia.

Normal bone marrow and blood cells

To understand the different types of leukemia, it helps to know something about the bone marrow and blood.

Bone marrow

Bone marrow is the soft, inner part of bones. It is where new blood cells are made. In babies, new blood cells are made in nearly all of the bones of the body. But by the teenage years they are made mostly in the flat bones (the skull, shoulder blades, ribs, hip bones, and back bones.

Bone marrow is made up of a small number of blood-forming cells (blood stem cells), other early forms of blood cells, fat cells, and tissues that help the blood cells grow. Early blood cells can grow to become red blood cells, white blood cells, or platelets.

Types of blood cells

Red blood cells carry oxygen from the lungs to all other tissues of the body and take carbon dioxide back to the lungs to be removed.

White blood cells help the body fight infections. There are many types of white blood cells, but the main types are:

- Lymphocytes
- Granulocytes
- Monocytes

Platelets are actually pieces that break off from certain bone marrow cells. Platelets help stop bleeding by plugging holes in blood vessels caused by cuts or bruises.

Types of leukemia in children

Leukemia can be either fast growing (acute), or slower growing (chronic). Almost all leukemia in children is acute.

Acute leukemias

There are 2 main types of acute leukemia:

- **Acute lymphocytic leukemia (ALL)**, also called *acute lymphoblastic leukemia*, accounts for about 3 out of 4 childhood leukemias. ALL starts from early forms of lymphocytes in the bone marrow.
- **Acute myelogenous leukemia (AML)**, also called *acute myeloid leukemia*, accounts for most of the remaining cases. This leukemia starts from the cells that form white blood cells (other than lymphocytes), red blood cells, or platelets.
- **Hybrid or mixed lineage leukemias** are rare. The cells have features of both ALL and AML. In children they are most often treated like ALL and usually respond to treatment like ALL.

Both ALL and AML have different subtypes as well.

Chronic leukemias

Chronic leukemias are much more common in adults than in children. They are divided into 2 main types:

- **Chronic myeloid leukemia (CML)** is rare in children.

- **Chronic lymphocytic leukemia (CLL)** is almost never seen in children.

Juvenile myelomonocytic leukemia (JMML)

This rare type of leukemia is neither chronic nor acute. It's not as fast growing as AML or as slow as CML. It occurs most often in children under age 4. Symptoms can include pale skin, fever, cough, easy bruising or bleeding, trouble breathing (from too many white blood cells in the lungs), and a swollen spleen and lymph nodes.

How common is childhood leukemia?

Leukemia is the most common cancer in children and teens. It accounts for almost 1 in 3 cancers in children. Even so, childhood leukemia is a rare disease.

About 3 out of 4 leukemias among children and teens are acute lymphocytic leukemia (ALL). Most of the rest are acute myelogenous leukemia (AML).

ALL is most common in early childhood, peaking in children between 2 and 4 years old. AML is more spread out across the childhood years, although it is slightly more common during the first 2 years of life and during the teen years.

Chronic leukemias are rare in children. Most of these are chronic myelogenous leukemia (CML), which tends to occur more in teens than in younger children.

Juvenile myelomonocytic leukemia (JMML) usually occurs in young children, with an average age of about 2.

What are the risk factors for childhood leukemia?

A risk factor is something that increases a person's chance of getting a disease. Different cancers have different risk factors.

Lifestyle risk factors such as diet, body weight, physical activity, and tobacco use play a major role in many adult cancers. But these factors often take many years to affect cancer risk, and they are not thought to play much of a role in childhood cancers, including leukemias.

There are a few known risk factors for childhood leukemia. But most children with leukemia do not have any known risk factors, and the cause of their cancer is not known at this time.

Genetic risk factors

Genetic risk factors are those that are part of our genes, which control nearly everything our cells do. Certain changes in our genes can cause bone marrow stem cells to develop into leukemia. These changes are most often inherited from our parents. Some genetic factors increase the risk of childhood leukemia, but most leukemias are not linked to any known genetic causes.

Inherited syndromes

Some inherited disorders increase a child's risk of leukemia:

- Li-Fraumeni syndrome
- Down syndrome
- Neurofibromatosis
- Fanconi anemia
- Ataxia-telangiectasia
- Wiskott-Aldrich syndrome
- Bloom syndrome
- Schwachman-Diamond syndrome

Having a brother or sister with leukemia

Brothers and sisters of children with leukemia have a slightly higher chance of getting leukemia, although the overall risk is still low. The risk is much higher among identical twins.

Having a parent who develops leukemia as an adult does not seem to raise a person's risk of leukemia.

Lifestyle risk factors

Lifestyle risk factors such as diet and exercise play a very small role (if any) in childhood cancer risk, even though they are important in adult cancers. Some studies have suggested that a mother drinking a lot of alcohol during pregnancy might increase the risk of leukemia in her child, but not all studies have found such a link.

Environmental risk factors

Environmental risk factors are things around us such as radiation and certain chemicals, which increase the risk of getting diseases like leukemia.

Radiation

Exposure to high levels of radiation is a risk factor for childhood leukemia.

It is not known how much risk there might be when children are exposed to lower levels of radiation, such as from x-rays or CT scans. Any increase in risk is likely to be small, but to be safe, most doctors do not order these tests for pregnant women or children unless they are really needed.

Exposure to chemo drugs and certain other chemicals

Children and adults who were treated with chemo for other cancers have a higher risk of getting a second cancer such as AML later in life. These leukemias usually develop within 5 to 10 years of treatment and tend to be hard to treat.

Exposure to chemicals like benzene (a solvent used in the cleaning industry and in the making of some drugs, plastics, and dyes) may cause acute leukemia in adults and, rarely, in children. Chemical exposure is more strongly linked to an increased risk of AML than to ALL.

Some studies have found a possible link between childhood leukemia and household exposure to pesticides, either during pregnancy or early childhood. More research is needed to try to confirm these findings.

Weakened immune system

Children who are getting drugs to suppress their immune systems (mainly children who have had organ transplants) have a higher risk of certain cancers, including ALL.

Other possible risk factors

A few studies have suggested that some childhood leukemias might be caused by a combination of genetic and environmental factors. For example, certain genes normally control how our bodies break down and get rid of harmful chemicals. Some people have different versions of these genes that make them less effective. Children who inherit these genes may not be as able to break down harmful chemicals if they are exposed to them. The combination of genetics and exposure might increase their risk for leukemia.

Many other possible risk factors have been studied, such as living near power lines or nuclear power plants, or having certain infections early in life. But so far, most studies have not found strong links between any other risk factors and childhood leukemia.

Can childhood leukemia be prevented?

Most children with leukemia have no known risk factors, so there is no sure way to prevent these cancers.

For some children, treatment with chemotherapy (chemo) or radiation for other, earlier cancers may cause leukemia later on. But the clear need to treat life-threatening diseases with chemo, radiation therapy, or organ transplant must be balanced against the small chance of developing leukemia several years later.

X-rays or CT scans done before birth or during childhood use much lower levels of radiation than those used for cancer treatment. If there is any increase in risk from these tests, it is likely to be very small, but to be safe, most doctors advise that pregnant women and children not get these tests unless they are really needed.

Because the cause of most cases of leukemia is not known, parents of children with leukemia need to know that there is nothing they could have done to prevent this illness.

How is childhood leukemia found?

At this time, there are no special tests advised for most children to help find leukemia early. The best way to find the disease early is for the parents to call the doctor right away if they notice that their child has any of the symptoms listed below.

Careful, regular medical checkups are important for children who are at higher risk of leukemia. This includes children who have been treated with chemotherapy (chemo) or radiation therapy for an earlier cancer, children who have certain genetic conditions (such as Li-Fraumeni syndrome or Down syndrome), and children who have had organ transplants.

Signs and symptoms of childhood leukemia

Childhood leukemia is often found because a child has symptoms that prompt a visit to the doctor.

Keep in mind that many of the symptoms listed here are most often caused by other problems – not leukemia. Still, it’s important to let your child’s doctor know about them so that the cause can be found and treated, if needed.

Most of the signs and symptoms of leukemia result from a lack of normal blood cells. This happens because the cancer cells crowd out the normal cells that make new blood cells in the bone marrow. The leukemia cells may also spread to other parts of the body, which can also cause symptoms.

Symptoms of leukemia can include:

- Frequent infections
- Fever
- Feeling tired or weak
- Feeling cold
- Feeling dizzy or lightheaded
- Headaches
- Shortness of breath
- Pale skin
- Easy bruising and bleeding (such as nosebleeds or bleeding gums)
- Bone or joint pain
- Swelling of the belly
- Loss of appetite and weight loss
- Swollen lymph nodes
- Coughing or trouble breathing
- Swelling of the face and arms
- Headache, seizures, or vomiting
- Rashes or gum problems

Again, most of these symptoms are more likely to be caused by something other than leukemia, but it’s still important to have them checked by a doctor.

Tests used to find leukemia

If your child has symptoms that might be caused by leukemia, the doctor will want to do certain tests to find out if it is leukemia and, if so, what type it is. That way, treatment can be tailored to provide the best chance of success.

Medical history and physical exam

The doctor will want to know how long your child has had symptoms and might also ask about possible risk factors for leukemia.

The doctor will then check your child for any swollen lymph nodes, areas of bleeding or bruising, or signs of infection. The eyes, mouth, and nervous system may also be examined thoroughly. The doctor will feel the belly for signs of a swollen spleen or liver.

The doctor may also get a blood sample from a vein or from a “finger stick” to check your child’s blood cell counts (see below). If these are not normal and the doctor thinks your child might have leukemia, he or she could refer you to a childhood cancer doctor (a *pediatric oncologist*), who may run one or more tests.

Types of tests used to look for leukemia in children

Blood cell counts: Most children with leukemia have too many white blood cells and not enough red blood cells or platelets in their blood. The white blood cells they do have are often young blood cells called *blasts* that normally stay in the bone marrow until they are mature. Finding these blast cells in the blood, or finding very few white blood cells at all, can also make the doctor suspect leukemia. But usually a sample of bone marrow will need to be taken to be sure.

Bone marrow aspiration and biopsy: Bone marrow samples are taken by doing a bone marrow aspiration and biopsy – usually at the same time. The samples are most often taken from the hip bones, but sometimes they may be taken from other bones.

These tests use thin, hollow needles to remove small amounts of bone marrow. The area around the bone is numbed, and the child may be given a drug make them sleep during the test. The samples are sent to a lab to see if there are leukemia cells in the bone marrow.

These tests are used to find out if a child has leukemia, but they can also be used later to see if the leukemia is responding to treatment.

Spinal tap (lumbar puncture): This test is done to look for leukemia cells in the liquid around the brain and spinal cord (*cerebrospinal fluid* or *CSF*).

For this test, the doctor first numbs an area in the lower part of the back over the spine. Often the doctor gives the child medicine to make him or her sleep during the test. A small hollow needle is placed between the bones of the spine to draw out some of the fluid, which is checked for leukemia cells.

For children already known to have leukemia, a lumbar puncture can also be used to give chemotherapy drugs into the CSF to try to prevent or treat the spread of leukemia to the spinal cord and brain.

Lymph node biopsy: This test is rarely needed for children with leukemia. For this test, a whole lymph node is removed. If the node is near the skin, this is a simple operation. But it may be more complex if the node is inside the chest or belly. Most often the child will need general anesthesia (where the child is in a deep sleep).

Lab tests for leukemia

A doctor with special training will look at all of the test samples (blood, bone marrow, CSF, and lymph node tissue) under a microscope. The doctor looks at the size and shape of the cells as well as other features to tell what type they are.

A key factor is whether or not the cells look mature. Having a lot of immature cells (blasts) in the sample, especially in the blood, is a typical sign of leukemia.

The doctor also might use a number of other lab tests to diagnose and classify leukemia. You might hear some of the following terms used:

- Cytochemistry
- Flow cytometry
- Immunohistochemistry
- Cytogenetics
- FISH
- PCR

These tests are explained in our detailed guide, *Childhood Leukemia.*

Other blood tests: If the child does have leukemia, other blood tests will be done to measure certain chemicals in the blood to see how well the liver, kidneys, and other organs are working. Tests may also be done to check for infections so they can be treated right away.

Imaging tests

Imaging tests take pictures of the inside of the body. Leukemia doesn’t usually form tumors, so imaging tests aren’t as useful as they are for other types of cancer. But some of these tests might be done in children with leukemia to get a better idea of the extent of the disease or to look for other problems like infections.

Chest x-ray: A chest x-ray can help tell if the thymus or lymph nodes in the chest are swollen. It can also help look for pneumonia if the child seems to have a lung infection.

CT (computed tomography) scan: CT scans (sometimes called CAT scans) use x-rays to make detailed pictures of the inside of the body. This test can help tell if the leukemia has spread into lymph nodes in the chest or to organs like the spleen or liver.

PET/CT scan: Some machines combine the CT scan with a PET (positron emission tomography) scan. For a PET scan, a form of a slightly radioactive sugar is injected into the blood. Leukemia cells in the body are growing quickly, so they absorb large amounts of the sugar. A special camera can then create a picture showing areas of radioactivity in the body. The PET/CT scan combines the 2 pictures to give the doctor more details about any areas of cancer.

MRI (magnetic resonance imaging): An MRI is like a CT scan except that magnets and radio waves are used to make the pictures instead of x-rays. MRI scans are helpful in looking at the brain and spinal cord.

MRI scans take longer than CT scans – often up to an hour. Your child may have to lie inside a narrow tube, which can be hard for some children. Drugs are sometimes needed to help them sleep for this test. Newer, more open MRI machines may be another option, but your child will still have to lie still.

Ultrasound: Ultrasound uses sound waves to make a picture of the inside of the body. Ultrasound can be used to look for enlarged lymph nodes or organs inside the belly. This is a fairly easy test to have done. Your child simply lies on a table, and a technician moves a sort of wand over the part of the body being looked at.

Bone scan: This test is not done often for childhood leukemias, but it may be useful if the child has bone pain that might be caused by infection or cancer in the bones. It is done in a way much like a PET scan. If the child has already been found to have leukemia or if a PET scan has already been done, there is often no need for this test.

Classifying childhood leukemia

For most types of cancer, determining the stage (extent) of the cancer is very important. The stage is based on the size of the tumor and how far the cancer has spread. But leukemia is not staged like most other cancers. The cancer starts in the bone marrow and quickly spreads to the blood, so leukemia cells are already throughout the body. The major concern is whether the leukemia cells have also started to collect in other organs such as the liver, spleen, lymph nodes, or central nervous system (brain and spinal cord).

For instance, if the cancer cells have spread to the central nervous system in large numbers, they can be seen under a microscope in samples of the cerebrospinal fluid (CSF), the fluid that surrounds the brain and spine. If that has happened, treatment will need to be more intense in order to kill these cells.

The most important factor for leukemias is figuring out the type (such as ALL or AML) and subtype of the leukemia. This is done by testing samples of the blood, bone marrow,

and sometimes lymph nodes or CSF. Figuring out the exact type and subtype of leukemia is a complex process that can be hard even for doctors to understand. For more detailed information, please see *Childhood Leukemia*.

Acute lymphocytic leukemia (ALL)

The subtypes of ALL are based on the type of lymphocyte (B cell or T cell) the leukemia cells come from and how mature they are. In most children with ALL, the leukemia starts in B cells. The main subtypes of ALL in children are:

- Early pre-B ALL (pro-B ALL)
- Common ALL
- Pre-B ALL
- Mature B-cell ALL (Burkitt leukemia)
- T-cell ALL

Acute myelogenous leukemia (AML)

AML has many subtypes, based on the type of cell involved and how mature it is. The subtypes of AML are classified by how they look under the microscope and on the changes in the genes or chromosomes in the leukemia cells.

One subtype of AML, known as *acute promyelocytic leukemia* (APL), is treated differently than the other subtypes and tends to have a better outlook.

Chronic myelogenous leukemia (CML)

Chronic myelogenous leukemia (CML) is often a slower-growing cancer. CML is not common in children, but it can occur.

The course of CML is divided into 3 phases, based mainly on the number of immature white blood cells (blasts) seen in the blood or bone marrow. If the leukemia is not cured with treatment, it can progress to more advanced phases over time.

- Chronic phase
- Accelerated phase
- Blast phase (blast crisis)

If you have questions about what phase your child’s CML is in, be sure to have the doctor explain it to you.

Prognostic factors in childhood leukemia

Prognostic factors are certain differences among patients that help predict how well they will respond to treatment. Knowing these factors helps the doctor decide whether to use standard treatment or more intense treatment. Prognostic factors seem to be more important in ALL than in AML.

Prognostic factors for ALL

ALL is often classified as standard-risk, high-risk, or very high-risk. Children at higher-risk are given more intense treatment.

There are many factors that can be used to help determine a child's risk, but the first 2 on this list are the most important. Keep in mind that many children with one or more poor factors can still be cured.

- The child's age when diagnosed
- White blood cell count
- Subtype of ALL
- The child's gender and race
- If the leukemia has spread to certain organs
- If there are chromosome changes in the leukemia cells
- How quickly the leukemia responds to treatment

Prognostic factors for AML

Prognostic factors are not quite as important for AML as they are for ALL. These factors can include:

- The child's age when diagnosed
- White blood cell count
- Whether the child has Down syndrome
- The child's body weight
- Subtype of AML
- The child's race
- If there are certain chromosome changes in the leukemia cells

- Whether the leukemia is a result of treatment for another cancer
- How quickly the leukemia responds to treatment

For more detailed information on these factors, please see *Childhood Leukemia*.

How is childhood leukemia treated?

This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.

The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.

Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

Children and teens with leukemia and their families have special needs. These needs can be met best by cancer centers for children and teens, working closely with the child's primary care doctor. These centers offer the advantage of being treated by teams of specialists who know the differences between cancers in adults and those in children and teens, as well as the special needs of younger people with cancer.

For childhood leukemias, this team is often led by a pediatric oncologist, a doctor who treats children's cancers. Many other doctors, nurses, and other specialists might be involved in your child's care as well.

Going through cancer treatment with a child often means meeting lots of specialists and learning about parts of the medical system you probably haven't had contact with before. You can find out more about this in *Children Diagnosed With Cancer: Understanding the Health Care System.*

Your child's cancer care team will talk to you about treatment options. The most important factor in choosing a treatment is the type of leukemia, although other factors also play a role.

The main treatment for childhood leukemia is chemotherapy (chemo). Sometimes this is given along with a stem cell transplant. Other treatments such as targeted drugs, surgery, and radiation treatment may be used in some cases.

Be sure to ask your cancer care team about any side effects your child might have from treatment. They can tell you about common side effects, how long they might last, and how serious they might be.

Be sure to tell your child's doctor about any drugs, herbal remedies, or other things you might be giving your child. These could affect how well the treatment works.

For more on how a specific type of childhood leukemia is treated, see the following sections:

- Treatment of acute lymphocytic (lymphoblastic) leukemia (ALL)
- Treatment of acute myeloid leukemia (AML)
- Treatment of acute promyelocytic leukemia (APL)
- Treatment of juvenile myelomonocytic leukemia (JMML)
- Treatment of chronic myelogenous leukemia (CML)

Immediate treatment of childhood leukemia

Some children are very ill when they are found to have leukemia. Low blood counts can result in serious problems such as infections, bleeding, and even heart failure. Antibiotics, other drugs, and blood transfusions might be needed right away to treat or prevent some of these problems before the leukemia treatment begins.

Surgery for childhood leukemia

Surgery has only a small role in treating leukemia. This is because leukemia is a disease of blood and bone marrow and can't be cured with surgery.

Surgery may be used before chemotherapy to put a small plastic tube into a large vein. The tube, called a *central venous catheter* or *venous access device* (VAD), allows medicines such as chemo to be given and blood samples to be removed without the need for repeated needle sticks. The end of the tube stays just under the skin or sticks out in the chest area or upper arm. Parents will be taught how to care for the VAD.

In cases where a boy with leukemia has a relapse of the disease in a testicle, surgery may be done to remove the testicle (along with giving chemo to treat the rest of the body).

For more on surgery as a treatment for cancer, see *A Guide to Cancer Surgery*.

Radiation treatment for childhood leukemia

Radiation therapy uses high-energy radiation to kill cancer cells. It is not always needed to treat leukemia, but it can be used in different situations:

- It can be used to try to prevent or treat cancer in the brain or in the testicles.
- It can be used, rarely, to shrink a tumor that is pressing on the windpipe. But chemotherapy is often used instead since it may work faster.

- Radiation to the whole body is often an important part of treatment before a stem cell transplant. (See “High-dose chemotherapy and stem cell transplant for childhood leukemia.”)

Radiation therapy is much like getting an x-ray, but the radiation is stronger. The procedure itself is painless, but some younger children might need to be sedated to make sure they don’t move during the treatment. Each treatment lasts only a few minutes, although the setup time – getting your child into place for treatment – usually takes longer.

Possible side effects

The possible short-term side effects depend on where the radiation is aimed. It can cause sunburn-like skin changes and hair loss in the treated area. Radiation to the belly (abdomen) can sometimes cause nausea, vomiting, or diarrhea. Radiation to large parts of the body can cause fatigue and an increased risk of infection.

Longer-term side effects are also possible and are described in the section “Long-term effects of treatment for childhood leukemia.”

More information can be found in the Radiation Therapy section of our website, or in *Understanding Radiation Therapy: A Guide for Patients and Families.*

Chemotherapy for childhood leukemia

Chemotherapy (chemo) is the use of drugs to kill cancer cells. This is the main treatment for most types of leukemia.

Usually the drugs are given either into a vein, into the cerebrospinal fluid (CSF), or as pills. Once the drugs enter the blood, they spread throughout the body. Children might get several chemo drugs at different times during the course of treatment.

Doctors give chemo in cycles, with each cycle of treatment followed by a rest period. As a rule, AML treatment uses higher doses of chemo over a shorter period of time (usually less than a year), while ALL treatment uses lower doses over a longer period of time (about 2 to 3 years).

Possible side effects

Chemo drugs attack cells that are growing quickly, which is why they work against cancer cells. But other cells in the body, such as those in the lining of the mouth and intestines, hair, and bone marrow (where new blood cells are made) also grow quickly and are likely to be damaged by chemo. This can lead to side effects, such as:

- Hair loss

- Mouth sores
- Loss of appetite
- Diarrhea
- Nausea and vomiting
- Increased risk of infections (because of low white blood cell counts)
- Bruising and bleeding easily (from low platelet counts)
- Tiredness (caused by low red blood cell counts)

These side effects usually go away after treatment ends. And there are often ways to manage these side effects during treatment. For example, drugs can help prevent or reduce nausea and vomiting. Drugs known as *growth factors* are sometimes given to keep blood counts higher and reduce the chance of infection.

Tumor lysis syndrome can be a side effect of chemo. When large numbers of leukemia cells are killed, they break open and release their contents into the bloodstream. This can affect the kidneys, heart, and nervous system. Giving the child extra fluids and certain drugs that help rid the body of these toxins can help prevent this problem.

Some side effects depend on which drugs are used. Be sure to ask your child's doctor or nurse about any specific side effects you should watch for and about what you can do to help reduce them.

Possible long-term effects of chemo are described in "Long-term effects of treatment for childhood leukemia."

For more on chemotherapy, see the Chemotherapy section of our website, or our document *A Guide to Chemotherapy*.

Targeted therapy for childhood leukemia

In recent years, new drugs that are aimed at certain parts of cancer cells have been developed. These are called *targeted drugs*. They work differently from standard chemotherapy drugs. They sometimes work when chemo drugs don't, and they often have less severe side effects. Some of these drugs may be useful in certain types of childhood leukemia.

For example, drugs such as imatinib (Gleevec) and dasatinib (Sprycel) can be used to treat children with chronic myelogenous leukemia (CML), as well as a small portion of children with acute lymphocytic leukemia (ALL). These drugs are taken as pills. Possible side effects include diarrhea, nausea, muscle pain, feeling tired, and skin rashes. Often these side effects are mild. A common side effect is swelling around the eyes or in the

hands or feet. These drugs may also slow a child's growth, especially if used before puberty.

High-dose chemotherapy and stem cell transplant for childhood leukemia

Stem cell transplant (SCT) can sometimes be used for children whose chances of cure are poor with standard or even intense chemotherapy. SCT lets doctors use very high doses of chemo. The high doses of these drugs destroy the bone marrow, which keeps new blood cells from being made. This poses a threat to the child's life. But after treatment is finished, the child gets a transplant of blood-forming stem cells to replace the bone marrow.

Allogeneic stem cell transplant

The type of SCT used for childhood leukemia is known as an *allogeneic stem cell transplant*. In this type of transplant, the blood-forming stem cells come from the blood or bone marrow of another person.

Usually the donor is a brother or sister, but rarely the donor is an unrelated volunteer who has the same tissue type as the child. Stored stem cells from umbilical cord blood can also be used. These stem cells come from blood drained from the umbilical cord and placenta after a baby is born and the cord is cut.

To learn about how a stem cell transplant is done, see *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants).*

When SCT might be used

Acute lymphocytic (lymphoblastic) leukemia (ALL): SCT could be used for children whose ALL doesn't respond well to the first treatment or comes back soon after going into remission. SCT may also be advised for children with some less common forms of ALL.

Acute myeloid leukemia (AML): Because AML comes back more often than ALL, many doctors advise SCT for children with AML right after they have gone into remission, especially if the child has a brother or sister who can donate stem cells. If the cancer comes back after the first round of chemo, most doctors will suggest SCT as soon as the child goes into remission again. In either case, it is important that the leukemia is in remission before the transplant. Otherwise, it is more likely to return.

Other leukemias: SCT might also offer the best chance to cure some less common types of childhood leukemia, such as juvenile myelomonocytic leukemia (JMML) and chronic myelogenous leukemia (CML).

Practical points

A stem cell transplant is a complex treatment that can cause life-threatening side effects. If the doctors think your child might be helped by this treatment, it's important that it be done at a hospital where the staff has a lot of experience with the procedure.

Stem cell transplant often requires a long hospital stay and can be very expensive (often costing well over $100,000). Be sure to get a written approval from your insurer if your child is to have this treatment. Even if the transplant is covered by your insurance, your co-pays or other costs could easily amount to thousands of dollars. It's important to find out what your insurer will cover before the transplant to get an idea of what you might have to pay.

Side effects of SCT

Side effects from a stem cell transplant can be short-term or long-term.

Short-term side effects: Early side effects are those of high-dose chemotherapy, and can be severe. They can include:

- Low blood cell counts (with fatigue and an increased risk of infection and bleeding)
- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Diarrhea
- Hair loss

One of the most common and serious short-term effects is the increased risk of severe infection. Antibiotics are often given to try to prevent this. Other side effects, like low red blood cell and platelet counts, may mean that the patient will need blood product transfusions or other treatments.

Long-term and late side effects: Some side effects can last a long time. Sometimes they don't show up until months or even years after the transplant. Long-term side effects could include:

- Graft-versus-host disease (see below)
- Radiation damage to the lungs
- Problems with the thyroid or other hormone-making glands
- Problems with fertility

- Damage to bones or problems with bone growth
- Development of another cancer (including leukemia) years later

Graft-versus-host disease (GVHD) is a major concern of an allogeneic SCT. This happens when the donor immune system cells attacks the patient's own cells, mainly in the skin, liver, and digestive tract.

Symptoms can include severe skin rashes with itching and severe diarrhea. The liver and lungs can also be damaged. The patient may also become tired and have aching muscles. If severe enough, the disease can be fatal. Drugs that weaken the immune system are often given to try to keep GVHD under control.

You can find out more about long-term effects in the section "Long-term effects of treatment for childhood leukemia."

To learn more about stem cell transplants, see *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants).*

Treatment of children with acute lymphocytic leukemia (ALL)

The main treatment for children with acute lymphocytic (lymphoblastic) leukemia (ALL) is chemotherapy (chemo), which has 3 phases:

- Induction
- Consolidation (also called *intensification*)
- Maintenance

Children with ALL are treated by risk group status to make sure that the correct types and doses of chemo drugs are given.

Induction

The goal of induction is to bring about a *remission*. This means that leukemia cells are no longer found in bone marrow samples, the normal marrow cells return, and the blood counts become normal. (A remission is not the same as a cure.) More than 95% of children with ALL will go into remission after 1 month of treatment.

Treatment during this month is intense, and your child may spend some or much of this time in the hospital. Frequent doctor visits might also be needed.

All children will need to have spinal taps to put chemo right into the cerebrospinal fluid (CSF) to try to keep cancer from spreading to the brain and spinal cord. Some children may need radiation to the head, too, but doctors try to avoid this if they can because it may cause some problems in thinking and growth, no matter how low the dose.

Consolidation

The goal of this phase (also called *intensification*) is to get rid of leukemia cells in hidden places. This phase lasts about 1 to 2 months. Several chemo drugs are used, depending on the child's risk category. Some children may benefit from a stem cell transplant at this time.

Maintenance

If the leukemia stays in remission after the first 2 phases of treatment, this last phase can begin. The total length of therapy for all 3 phases is 2 to 3 years for most children with ALL. Because boys are at higher risk for relapse than girls, many doctors favor giving them several more months of treatment.

Treatment of residual disease

Treatment plans may change if the leukemia doesn't go away in the first few months. Soon after treatment has begun the doctor will check the child's bone marrow to see if the leukemia is going away. If not, treatment may be increased or given for a longer time. When the leukemia *seems* to have gone away, the doctor may do special blood tests to look for leukemia cells. If any are found, then once again, chemo may be increased or prolonged.

Treatment of recurrent ALL

If the leukemia comes back during or after treatment, the child will again be treated with chemo. This may include the same or different drugs, depending on how long the remission lasted. A stem cell transplant may be considered for children whose leukemia comes back soon after starting treatment, especially if there is a brother or sister who is a good match. Stem cell transplant may also be used for other children who relapse after a second course of chemo.

Some children have a relapse in which leukemia cells are found in one part of the body (such as the CSF or the testicles) but are not found in the bone marrow. These children may have intense chemo, sometimes along with radiation or surgery to the affected area.

If ALL doesn't go away completely or if it comes back after a stem cell transplant, it can be very hard to treat. For some children, newer types of immunotherapy (treatments that boost the body's immune response against the leukemia) might be helpful.

Treatment of children with acute myeloid leukemia (AML)

Treatment for most children with acute myeloid leukemia (AML) is in 2 phases:

- Induction
- Consolidation (intensification)

Compared to treatment for ALL, the treatment for AML uses higher doses of chemotherapy (chemo) but for a shorter time. Treatment is very intense and there is a risk of serious complications, so children with AML need to be treated in cancer centers or hospitals that have a lot of experience with this disease.

Induction

The combinations of chemo drugs used to treat AML are different from those used for ALL. Treatment is given over several days, and may be repeated until the bone marrow shows no more leukemia. This usually happens after 2 or 3 treatments. Often chemo is put into the cerebrospinal fluid (CSF), too.

Consolidation (intensification)

This phase begins after a remission when no more leukemia cells are seen in the bone marrow. High-dose chemo is given for at least several months.

Some children have a brother or sister who would be a good stem cell donor. For these children, a stem cell transplant is often recommended, especially if the risk of the leukemia coming back is high. For children with lower risk AML, some doctors recommend just giving high-dose chemo and holding off on the stem cell transplant in case the AML comes back after treatment.

Chemo is usually given into the CSF every 1 to 2 months for as long as this phase lasts.

An important aspect of treatment for AML is supportive care (nursing care, nutrition, antibiotics, blood transfusions, etc.). With this care, a high rate of remission can be achieved.

Treatment of refractory or recurrent AML

Less than 15% of children have *refractory AML* (leukemia that does not respond to initial treatment). These leukemias are often very hard to cure, so the doctor may recommend a stem cell transplant if it can be done.

The outlook for a child whose AML comes back after treatment tends to be slightly better than if a remission were never achieved. But this depends on how long the first remission lasted. The chance of a second remission is better if the first one lasted for at least a year, but long-term second remissions are rare without a stem cell transplant.

Most children whose leukemia has come back will be offered a clinical trial in the hope that if a remission is brought about, a stem cell transplant can then be done. Sometimes the doctor may suggest a stem cell transplant even without a remission.

Treatment of children with acute promyelocytic leukemia (APL)

Treatment of acute promyelocytic leukemia (APL) differs from usual AML treatment. Most children respond well to this treatment, which is given in 3 phases:

- Induction
- Consolidation (also called *intensification*)
- Maintenance

Induction

Many children with APL may have bleeding and blood-clotting problems, which can be serious. They may be given a “blood thinner” to help prevent or treat these problems.

Along with chemotherapy (chemo), children with APL get a drug related to vitamin A called ATRA (all-trans retinoic acid). ATRA can cause a problem called *differentiation syndrome*. It can include breathing problems due to fluid build-up in the lungs, low blood pressure, kidney damage, and severe fluid build-up elsewhere in the body. It can often be treated by stopping the ATRA for a while and giving a steroid.

Consolidation (intensification)

This is usually much like induction, using both ATRA and chemo. Because of the success of this treatment, stem cell transplant is not usually advised as long as the child stays in remission.

Maintenance

Children with APL may get maintenance therapy with ATRA, often with chemo, for about a year.

Relapsed APL

If APL comes back after treatment, most often it can be put into a second remission. Arsenic trioxide is a drug that works very well in this setting, but it can sometimes cause problems with heart rhythms. Children getting this drug need to have their blood mineral

levels watched closely. ATRA plus chemo may be another option. A stem cell transplant may be considered once a second remission is brought about.

Treatment of children with juvenile myelomonocytic leukemia (JMML)

JMML is fairly rare. A stem cell transplant offers the best chance to cure JMML and is the treatment of choice when possible. About half of the children with JMML who get a stem cell transplant are still free of leukemia after several years. Sometimes, even if the leukemia recurs, a second stem cell transplant can be helpful.

Because JMML is hard to treat with current chemo drugs, taking part in a clinical trial looking at newer drugs may be a good option for children who can’t get a stem cell transplant.

Treatment of children with chronic myelogenous leukemia (CML)

Chronic myelogenous leukemia (CML) is rare in children. Treatment in children is like treatment in adults.

Targeted drugs such as imatinib (Gleevec) and dasatinib (Sprycel) usually work well at keeping CML under control, often with less severe side effects than with chemo drugs. But these drugs do not seem to cure CML when used alone, and they must be taken every day.

If targeted drugs are no longer helpful, high-dose chemotherapy with a stem cell transplant offers the best chance for a cure. Doctors are now looking at whether adding targeted drugs to stem cell transplant plans can help increase cure rates.

To learn more about CML and its treatment, see *Leukemia--Chronic Myeloid Overview*.

Clinical trials for childhood leukemia

You may have had to make a lot of decisions since you’ve been told that your child has leukemia. One of the most important decisions you will make is choosing which treatment is best for your child. You might have heard about clinical trials being done for leukemia. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done to learn more about promising new treatments or procedures.

Clinical trials are one way to get state-of-the-art cancer care for your child. Sometimes they may be the only way to get access to some newer treatments. They are also the best way for doctors to learn better methods to treat cancer. Still, they might not be right for every child.

If you would like to learn more about clinical trials that might be right for your child, start by asking your doctor if your clinic or hospital conducts clinical trials. Children's cancer centers often conduct many clinical trials at any one time, and most children treated at these centers take part in a clinical trial as part of their treatment.

You can also call our clinical trials matching service for a list of studies that meet your child's medical needs. You can reach this service at 1-800-303-5691 or on our website at www.cancer.org/clinicaltrials. You can also get a list of current clinical trials by calling the National Cancer Institute (NCI) at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials website at www.cancer.gov/clinicaltrials.

Your child must meet the requirements of any clinical trial to take part in it. If he or she does qualify for a clinical trial, it is up to you whether or not to enter (enroll in) it. Older children, who can understand more, usually must also agree to take part in the clinical trial before the parents' consent is accepted.

To learn more about clinical trials, see our document *Clinical Trials: What You Need to Know*.

Complementary and alternative therapies for childhood leukemia

You might hear about ways to treat leukemia or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to social media groups and websites may offer ideas for what might help. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

What are complementary and alternative therapies?

Not everyone uses these terms the same way, and they are used to refer to many different methods. We use *complementary* to refer to treatments that are used *along with* your regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

Complementary methods: Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help people feel better. Some examples of methods used along with regular treatment are: art therapy or play therapy to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been proven not to be helpful, and a few might even be harmful.

Alternative treatments: Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may be harmful, or have life-threatening side effects. But the biggest danger in most cases is that your child could lose the chance to be helped by standard medical treatment. Delaying or interrupting your child's medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

Finding out more

It's easy to see why parents who have children with cancer think about alternative methods. You want to do all you can to fight the cancer, and the idea of a treatment with no few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most alternative methods have not been tested and proven to work in treating cancer.

As you consider your options, look for "red flags" that might suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a "secret" that requires you to visit certain providers or travel to another country? Also be sure to talk to your cancer care team about any method you are thinking about using.

You can find more tips on what to look for and how to make these decisions in the "Complementary and Alternative Medicine" section of our website.

The choice is yours

You always have a say in how your child is treated. If you want to consider a non-standard treatment, learn all you can about the method and talk to your child's doctor about it. With good information and the support of your child's health care team, you may be able to safely use the methods that can help your child while avoiding those that could be harmful.

What are some questions you can ask the doctor about childhood leukemia?

We encourage you to have honest, open talks with your child's cancer care team. Feel free to ask any question, no matter how small it might seem. Here are some questions you might want to ask:

- Would you write down exactly what kind of leukemia my child has?
- Are there any factors that might affect my child's outlook?
- Do we need any other tests before we can decide on treatment?

- Are there other doctors we need to see?
- How much experience do you have treating this type of leukemia?
- Should we get a second opinion? Can you recommend someone?
- What are our treatment choices?
- What do you recommend and why?
- Should we think about a stem cell transplant?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- How long will treatment last? What will it be like?
- How much of the treatment will need to be done in the hospital?
- How will treatment affect our daily lives (school, work, etc.)?
- What are the risks or side effects of the treatments you recommend?
- Which side effects start shortly after treatment and which ones may happen later on?
- Will treatment affect my child's ability to learn, grow, and develop?
- Will treatment affect my child's future ability to have children?
- What are the chances of curing the leukemia?
- What would our options be if the treatment doesn't work or if the leukemia comes back?
- What type of follow-up will we need after treatment?
- How will we pay for treatment? Will our insurance cover all or part of it?
- Can we talk to support groups or other families who have been through this?

Along with these sample questions, be sure to write down your own. For instance, you might want to ask if your child qualifies for any clinical trials. You may also want to ask about the typical costs of treatment, and what is likely to be covered by insurance.

Also keep in mind that doctors are not the only ones who can give you information. Other health care professionals, such as nurses and social workers, may have the answers to some of your questions. You can find out more about speaking with your health care team in *Talking With Your Doctor*.

Moving on after treatment

During and after treatment for childhood leukemia, most families are concerned about the short and long-term effects of the leukemia and its treatment, and the chance of the leukemia coming back.

Of course, it's normal to want to put the leukemia and its treatment behind you and to get back to a life that doesn't revolve around cancer. But it's important to realize that follow-up care is a central part of this process that offers your child the best chance for recovery and long-term survival.

Follow-up exams

Follow-up exams are needed for several years after treatment. The doctor will watch for signs of leukemia, as well as for short-term and long-term side effects of treatment.

Checkups most often include careful physical exams, lab tests, and sometimes, imaging tests. These checkups will likely be monthly during the first year, and then less often for at least 5 years after treatment. After that, most children see their doctor at least yearly for a checkup.

If leukemia comes back, it is usually during treatment or within a year or so after treatment ends. It's unusual for an acute leukemia (ALL or AML) to come back if there are no signs of the disease within the next 2 years.

Follow-up care gives you a chance to discuss questions and concerns that come up during and after your child's recovery. For example, almost any cancer treatment can have side effects. Some go away soon after treatment, but others can last a long time, or might not even show up until years later. It's important to report any new symptoms to the doctor right away, so that the cause can be found and treated, if needed.

Keeping good medical records

As much as you might want to put the experience behind you once treatment is done, it's very important to keep good records of your child's medical care during this time. This can be very helpful later on as your child changes doctors. Gathering the details during or soon after treatment may be easier than trying to get them at some point in the future. Be sure the doctors have the following information (and always keep copies for yourself):

- A copy of the pathology reports from any biopsies or surgeries.
- If your child had surgery, a copy of the operative report.
- If your child stayed in the hospital, copies of the discharge summaries that the doctor wrote when your child was sent home.

- A list of the final doses of each drug your child had. (Certain chemo drugs have specific long-term side effects.)
- If radiation was given, a final summary of the dose and field.
- The names and contact information of the doctors who treated your child's leukemia.

It's also very important to keep health insurance coverage. Tests and doctor visits cost a lot, and even though no one wants to think of the leukemia coming back, this could happen.

Social and emotional issues during and after treatment of childhood leukemia

Social and emotional issues can come up both during and after treatment. Factors such as the child's age and the extent of treatment can play a role here.

Some children have emotional issues that need to be addressed during and after treatment. Depending on their age, they might also have some problems with daily activities and school work. These can often be helped with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help children after treatment.

Many experts advise that school-aged children attend school as much as possible. This can help them maintain a sense of daily routine and keep their friends informed about what is happening.

Friends can be a great source of support, but patients and parents should know that some people have misunderstandings and fears about cancer. Some cancer centers have school re-entry programs that can help. In these programs, health educators visit the school and tell students about the cancer, its treatment, and changes that the patient may go through. They also answer any questions from teachers and classmates. (For more information, see *Children Diagnosed With Cancer: Returning to School*.)

Centers that treat many children with leukemia often have programs to help new patients and their families meet others who have finished their treatment. This can give them an idea of what to expect during and after treatment, which can be very important.

Parents and other family members can also be affected, both emotionally and in other ways. Some common family concerns during treatment include financial stresses, traveling to and staying near the cancer center, the possible loss of a job, and the need for home schooling. Social workers and other professionals at cancer centers can help families sort through these issues.

During treatment, children and their families tend to focus on the daily aspects of getting through it and beating the leukemia. But once treatment is finished, a number of emotional concerns can arise. Some of these may last a long time and can include:

- Dealing with physical changes that can result from treatment
- Worries about the leukemia returning or new health problems developing
- Feelings of resentment for having had leukemia or having to go through treatment when others do not
- Concerns about being treated differently or discriminated against (by friends, classmates, coworkers, employers, etc.)
- Concerns about dating, marrying, and having a family later in life

No one chooses to have leukemia, but for many childhood leukemia survivors, the experience can have positive effects, helping to establish strong self-values. Other survivors may have a harder time recovering, adjusting to life after cancer, and moving on. It's normal to have some fear or other emotions after treatment, but feeling overly worried, depressed, or angry can affect many aspects of a young person's growth. It can get in the way of relationships, school, work, and other aspects of life. With support from family, friends, other survivors, mental health professionals, and others, many people who have survived cancer can thrive in spite of the challenges they've had to face.

Late and long-term effects of treatment for childhood leukemia

Just as the treatment of childhood leukemia requires a very special approach, so does the care and follow-up after treatment. The earlier the problems are found, the more likely it is they can be treated effectively.

Childhood leukemia survivors are at risk, to some degree, for several possible late effects of their treatment. This risk depends on a number of factors, such as the type of leukemia, the type and doses of treatment, and the child's age at time of treatment. It's important to discuss what these possible effects might be with your child's medical team so you know what to watch for and report to the doctor.

Second cancers: Children who have been treated for leukemia have a higher risk of getting other cancers later in life.

Heart and lung problems: Certain chemo drugs or radiation therapy to the chest can sometimes cause heart or lung problems later in life.

Learning problems: Treatment that includes radiation therapy to the brain or some types of chemotherapy may affect learning ability in some children.

Growth and development: Some treatments may affect a child's growth, so they may end up a bit shorter as adults. This is especially true after stem cell transplants. This can be helped by treatment with growth hormone, if needed.

Fertility issues: Cancer treatment might also affect sexual development and the ability to have children later in life. For more, see *Fertility and Women With Cancer* and *Fertility and Men With Cancer*.

Bone problems: Bone damage or thinning of the bones (osteoporosis) can result from the use of some steroid drugs.

There may be other possible problems from treatment. Your child's treatment team will review with you before starting treatment.

Long-term follow-up guidelines

To help improve follow-up care of childhood cancer survivors throughout their lives, the Children's Oncology Group (COG) has written long-term follow-up guidelines for doctors. These guidelines can help you know what to watch for, what types of screening tests should be done, and how late effects can be treated.

It's very important to discuss possible long-term health effects with your child's health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child's doctors about the COG survivor guidelines. You can also read them on the COG website: www.survivorshipguidelines.org. The guidelines are written for health care professionals. Patient versions of some of the guidelines are available (as "Health Links") on the site as well, but we urge you to discuss them with your doctor.

To learn more about possible late effects of treatment, see *Children Diagnosed With Cancer: Late Effects of Cancer Treatment*.

What's new in childhood leukemia research?

Research into all aspects of childhood leukemia is now being done at many medical centers and hospitals.

Genetics

Scientists are making great progress in understanding how changes in the genes inside bone marrow cells can cause them to change into leukemia cells. Today, there are much better tests for finding the disease and for telling exactly what kind of leukemia a child has and how well treatment is working. For example, one test (called *PCR*) can help tell how much of the leukemia has been destroyed by treatment, and whether a relapse will occur if further treatment is not given.

Clinical trials

Clinical trials are studying why some children with leukemia have a relapse, which children need more intense treatment, which drugs work the best, and whether natural substances made by the body can help the immune system fight the leukemia cells. These and many other issues are being addressed in clinical trials. Answers to these questions will mean better treatment of childhood leukemia in the future.

Immunotherapy

Immunotherapy is treatment that boosts a child's own immune system to help fight leukemia. Some types of immunotherapy have shown a lot of promise in treating ALL, even when other treatments are no longer working.

Chimeric antigen receptor (CAR) T-cell therapy: In this treatment, immune cells called T cells are removed from the child's blood and altered in the lab to help them attack leukemia cells. The T cells are then grown in the lab and given back into the child's blood.

This technique has shown very encouraging results in early clinical trials against some advanced, hard-to-treat cases of ALL. In many children the leukemia could no longer be detected after treatment, although it's not yet clear if these children have been cured.

Monoclonal antibodies: Man-made versions of immune proteins, called *monoclonal antibodies*, can be designed to attack a specific target, such as a protein on the surface of leukemia cells.

An example is blinatumomab (Blincyto), a special kind of monoclonal antibody that can attach to 2 different proteins at the same time. This drug acts as a tiny bridge to bring immune cells and leukemia cells together, which is thought to cause the immune system to attack the leukemia cells. Early results with this drug against B-cell ALL have been promising, although so far it has been studied more in adults than in children.

To learn more about childhood leukemia

From your American Cancer Society

Here is more information you might find helpful. You can read these online, or order free copies from our toll-free number, 1-800-227-2345.

Children with cancer

Children Diagnosed With Cancer: Dealing with Diagnosis (also in Spanish)

Pediatric Cancer Centers (also in Spanish)

Children Diagnosed With Cancer: Understanding the Health Care System (also in Spanish)

Children Diagnosed With Cancer: Financial and Insurance Issues

Children Diagnosed With Cancer: Returning to School

Children Diagnosed With Cancer: Late Effects of Cancer Treatment

Health Professionals Associated With Cancer Care

Talking With Your Doctor (also in Spanish)

Coping with cancer

After Diagnosis: A Guide for Patients and Families (also in Spanish)

Family and Medical Leave Act (FMLA) (also in Spanish)

Nutrition for Children With Cancer (also in Spanish)

What Happened to You, Happened to Me (children's booklet)

When Your Brother or Sister Has Cancer (children's booklet)

When Your Child's Treatment Ends: A Guide for Families (booklet)

Cancer treatment information

A Guide to Chemotherapy (also in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

Clinical Trials: What You Need to Know (also in Spanish)

Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants) (also in Spanish)

Side effects from cancer and its treatment

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also in Spanish)

Nausea and Vomiting

Guide to Controlling Cancer Pain (also in Spanish)

Anemia in People With Cancer

Fatigue in People With Cancer

Fertility and Women With Cancer

Fertility and Men With Cancer

Books

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at cancer.org/bookstore to find out about costs or to place an order.

National organizations and websites*

Along with the American Cancer Society, other sources of information and support include:

Websites for parents and adults

American Childhood Cancer Organization (formerly Candlelighters)
Toll-free number: 1-855-858-2226
Website: www.acco.org

> Offers information for children and teens with cancer, their siblings, and adults dealing with children with cancer. Also offers books and a special kit for children newly diagnosed with cancer, as well as some local support groups.

Children's Oncology Group (COG)
Website: www.childrensoncologygroup.org

> Provides key information from the world's largest organization devoted to childhood cancer research to help support children and their families from the time of diagnosis, through treatment, and beyond. Also has a searchable database to find the COG center closest to you.

CureSearch for Children's Cancer
Toll-free number: 1-800-458-6223
Website: www.curesearch.org

> Provides up-to-date information about childhood cancer from pediatric cancer experts. Has sections on the website for patients, families, and friends to help guide them on how to support the child with cancer.

Leukemia & Lymphoma Society
Toll-free number: 1-800-955-4572
Website: www.lls.org

Has an Information Resource Center, staffed by health care professionals, available via the toll free number; free publications on all forms of leukemia and other related topics (some materials are also available in Spanish); family support groups for patients, family, and friends are available in most geographical areas; free education teleconferences and webcasts (schedule is available on the website); also has a program to assist patients with significant financial need to cover some of the costs associated with transportation, drug co-pays, and insurance premiums.

National Cancer Institute
Toll-free number: 1-800-4-CANCER (1-800-422-6237)
TTY: 1-800-332-8615
Website: www.cancer.gov

Provides accurate, up-to-date information about cancer for patients and their families, including clinical trials information. Offers a special booklet for teen siblings of a child with cancer at: www.cancer.gov/cancertopics/when-your-sibling-has-cancer.

National Children's Cancer Society, Inc.
Toll-free number: 1-800-5-FAMILY (1-800-532-6459)
Website: www.children-cancer.org

Services include an online support network for parents of children with cancer, educational materials, and financial assistance for treatment-related expenses.

Websites for teens and children

Starlight Children's Foundation
Phone number: 1-310-479-1212
Website: www.starlight.org

Website has animated stories and interactive programs to teach kids about chemo and procedures that are done in the hospital; also has videos specifically for teens and provides a safe, monitored online support group for teens with cancer.

Group Loop (a subsite of the **Cancer Support Community** just for teens)
Toll-free number: 1-888-793-9355
Website: www.grouploop.org

An online place for teens with cancer or teens who know someone with cancer to connect with other teens away from the pressures of classes, responsibilities, and treatment schedules. Has online support groups, chat rooms, information, and more.

Teens Living with Cancer
Website: www.teenslivingwithcancer.org

An online-only resource dedicated to teens coping with a cancer diagnosis and treatment. It focuses on teen issues and provides resources to support teens, their families, and friends.

SuperSibs! Powered by Alex's Lemonade Stand
Toll-free number: 1-866-333-1213
Website: www.supersibs.org

Supports, honors, and recognizes brothers and sisters of children diagnosed with cancer so they may face the future with strength, courage, and hope.

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for cancer-related information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

Last Medical Review: 5/13/2015
Last Revised: 5/13/2015

2015 Copyright American Cancer Society

For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org