

Lymphoblastic Leukemia

ONCOLOGY SERIES

Acute Lymphoblastic Leukemia

A HANDBOOK FOR FAMILIES

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WHAT IS LEUKEMIA?

Leukemia is a cancer of the blood and bone marrow. The bone marrow is the soft, spongy tissue found inside of bones where normal blood cells are made. The blood cells that are made in the bone marrow include the white blood cells (WBCs), red blood cells (RBCs), and platelets.

Each type of blood cell has its own job in the body. WBCs are the infection-fighting cells. RBCs provide oxygen and energy to the body. Platelets help blood to clot (or thicken); the blood's ability to clot is important during certain situations, such as when you have a cut.

Leukemia occurs as a result of abnormal growth of immature blood cells. These cells are called *blast cells*. These immature cells grow out of control, crowd out the normal cells (WBCs, RBCs, and platelets) in the bone marrow, and eventually spill out into the bloodstream. As a result, leukemia may be found in other parts of the body such as the lymph nodes, liver, spleen, central nervous system (which is the brain and spinal cord), testicles, skin, and other organs.

Bone Marrow

The bone marrow is where blood cells and the immune system develop. Bone marrow produces stem cells, which are the cells that all of our blood cells come from; sometimes they are called "mother" cells. Stem cells mature into two different types of cells: lymphoid cells or myeloid cells.

Lymphoid stem cells further develop into lymphocytes. These cells make up the body's immune system, which is important in fighting infection and attacking cancer cells. Myeloid cells further develop into RBCs, platelets, or other types of WBCs called *granulocytes*.



Leukemia occurs in cells that develop from either the lymphoid or myeloid cell line.

White Blood Cells (WBCs)

WBCs, also called *leukocytes*, help to defend the body against infections. Infections can be caused by bacteria, viruses, and fungi. The three different types of WBCs are lymphocytes, granulocytes, and monocytes.

Lymphocytes are a type of WBC that develop from the lymphoid cell line and help to fight infections. The three types of lymphocytes are B lymphocytes (B cells), T lymphocytes (T cells), or natural killer cells (NK cells). B cells and T cells help the body by developing antibodies to fight infection. NK cells fight viruses and attack cancer cells.

Granulocytes are a type of WBC that develop from the myeloid stem cell. They help destroy infections caused by bacteria.

Monocytes are a third type of WBC that are related to granulocytes. Monocytes help fight against bacteria by surrounding and digesting them. They also help lymphocytes identify germs.

Red Blood Cells (RBCs)

RBCs carry oxygen to all of the cells in the body. If the number of RBCs is low, a child may look pale and feel tired

and have headaches, dizziness, or a fast heartbeat. The number of RBCs is measured by a blood test measuring the hemoglobin level. A low level of RBCs is called *anemia*.

Platelets are the blood-clotting cells that are needed to stop bleeding and to form a clot. If the level of platelets in the blood is low, there is an increased chance of bleeding and bruising. A rash that looks like small red-purple freckles also may be seen. These freckles are called *petechiae*. A low level of platelets is called *thrombocytopenia*.

WHAT ARE THE TYPES OF LEUKEMIA?

There are several different types of leukemia, with two main classifications based on how quickly cells grow: acute leukemia and chronic leukemia.

Acute leukemia develops from young, immature cells called *blasts*. The blast cells divide frequently, causing the leukemia cells to grow and accumulate very quickly. The main types of acute leukemia are:

- Acute lymphoblastic leukemia (ALL)—a cancer that occurs in the lymphocytes, affecting either the T or B lymphocytes. This is the most common type of childhood leukemia.
- Acute myeloid leukemia (AML)—a cancer that occurs in the myeloid cells, usually affecting the WBCs; however, in some cases, it may involve the RBCs or platelets.
- A less common kind of cancer-biphenotypic leukemia-has features of both ALL and AML.

Chronic leukemia develops more slowly and occurs in more mature, abnormal cells. This type of leukemia is seen more often in adults than in children. The two main types of chronic leukemia are chronic myelogenous leukemia (CML) and chronic lymphoblastic leukemia (CLL). Treatment for chronic leukemia is very different than treatment for acute leukemia, and it is not discussed in this booklet.

HOW COMMON IS ACUTE LYMPHOBLASTIC LEUKEMIA (ALL)?

ALL is the most common cancer seen in children. It often is seen in young children and young adults, with most children diagnosed between 2 and 5 years of age. About 2,400 people develop ALL each year. Caucasian children are more likely to have ALL than African American children, and the likelihood is highest in Hispanic children. ALL is more common in boys than in girls. About 85% of children who develop ALL will survive.

Leukemia involving B-cell lymphocytes is the most common. Among children with ALL, 85% will have B-cell leukemia.

There are three types of B-cell ALL:

- Early pre-B (very immature B cells)
- Pre-B (immature B cells)
- B-cell (mature B cells, also called Burkitt's lymphoma).

Early pre-B and pre-B ALL are treated in the same way. Burkitt's lymphoma is only seen in 1%–2% of children with ALL; this type of ALL requires different, more intensive treatment that is given over a shorter period of time.

Leukemia involving the T-cell lymphocyte is seen in about 15% of childhood leukemia. At the time the diagnosis is made, children with T-cell ALL have a higher WBC count and a mass in the chest. Most commonly, T-cell ALL affects older children and boys.

WHAT CAUSES ALL?

All cells in the body contain genetic material called *chromosomes* that help cells to reproduce. Normal cells in the body grow and then die in a controlled way. Leukemia occurs when a chromosome is damaged, resulting in immature, rapidly dividing cells that do not die. In ALL, we do not know what causes chromosomes to become damaged.

Certain risk factors increase a person's chance of developing ALL. However, just having a risk factor does not mean a person will get cancer, and some people who develop cancer do not have any risk factors.

Possible risk factors for ALL include

- exposure to radiation before birth
- certain genetic disorders, such as Down syndrome
- previous chemotherapy treatment or taking other medications that weaken the immune system
- being born with certain immune-system problems.

WHAT ARE THE SIGNS AND SYMPTOMS OF LEUKEMIA?

The signs and symptoms of leukemia are noticed when leukemia cells are growing out of control and overcrowding occurs in the bone marrow. Symptoms may be different depending on the type of cell the marrow is (or is not) able to produce. Common symptoms seen in children include

- fever or unexplained infections
- easy bruising, bleeding, and petechiae (flat, pinpoint-sized red or purple dots on the skin)
- fatigue and general weakness
- bone or joint pain (limping or refusal to walk) that may come and go
- lumps (caused by swollen lymph nodes) often found in the neck, underarms, stomach, or groin
- swollen belly because of an enlarged liver or spleen
- decreased appetite/weight loss.

WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

The symptoms of ALL, such as looking pale, infections, or bleeding, usually prompt a visit to the pediatrician. Leukemia often is suspected when there are abnormal findings on a blood test called the *complete blood count* (CBC) or if abnormalities are noticed during a physical exam. To confirm the diagnosis of leukemia, additional testing will be needed. Tests that may be done are listed below.

Bone Marrow Aspiration and Biopsy

This test involves inserting a needle into the bone (often the hip bone) to remove a sample of the bone



marrow. Children receive sedation or special medicine to make them sleep during this procedure. The sample that is obtained is sent for several tests, including immuno-phenotyping, cytogenetics, and fluorescent in situ hybridization (FISH).

Immuno-Phenotyping

A sample from the bone marrow aspirate will show whether your child has T-cell or B-cell leukemia.

Cytogenetics

A sample from the bone marrow aspirate will show chromosome changes in the leukemia cells. Some leukemia cells will "swap" some of their genetic pieces from one chromosome to another. This is called a *translocation*. Certain translocations help predict the prognosis and risk group for children with leukemia. Results from this test may not be available for 1–2 weeks.

Fluorescent in Situ Hybridization (FISH)

FISH is a test that uses special fluorescent dyes that only attach to specific parts of chromosomes. The test can be used to look for specific changes in chromosomes in the leukemia cell. Results from this test may not be available for 1–2 weeks.

Lumbar Puncture (Spinal Tap)

Leukemia cells can hide in the spinal fluid, so a spinal tap is done to look for these cells. A needle is carefully inserted into the spinal canal to obtain a sample of cerebrospinal fluid to look for leukemia cells. Additionally, a lumbar (or lower back) puncture will be performed periodically throughout leukemia treatment to place chemotherapy drugs into the central nervous system to prevent or treat leukemia in the spinal fluid.

Chest X Ray

A chest X ray can help detect a mass or enlargement in the chest or lymph nodes in the chest, often seen in T-cell leukemia.

Testicular Biopsy

This test will be done if your doctor thinks that leukemia may be in the testicles. Typically, testicular involvement is suspected if there is a painless enlargement of the testicle. To obtain the biopsy, a needle is inserted into the testes to remove a small sample of tissue that will be examined under a microscope to look for leukemia cells. This is done in the operating room while your child is asleep. Only a small percentage of boys have testicular disease at initial diagnosis.

Imaging Tests

Imaging studies such as computerized tomography (CT) scans, magnetic resonance imaging (MRI), or ultrasound tests may be done to help determine if the cancer has spread to other parts of the body, such as the brain.

WHAT ARE 'STAGES'? WHAT ARE 'RISK GROUPS'?

In childhood leukemia, "risk groups" are used instead of a system of "stages." Your healthcare team will perform a series of tests to help determine your child's type of leukemia and risk group. Once your child is diagnosed with ALL, he or she will be assigned to a risk group based on his or her age, WBC count at diagnosis, leukemia in the spinal fluid, or leukemia in the testicles. This will allow the healthcare team to determine the treatment plan during the first month.

The initial risk groups at diagnosis are

- average or standard risk—Includes children 1 to 9.99 years old who have a WBC count lower than 50,000 at diagnosis
- high risk—Includes children younger than 1 year and 10 years or older or those with an initial WBC of 50,000 or higher at diagnosis. In addition, children with T-cell leukemia are classified in a higher-risk group.

Children younger than 1 year (365 days) or those with ALL involving T-cells or mature B-cell leukemia will be treated on different treatment plans.

The results from the cytogenetic testing and your child's response to the initial treatment also will be used to further determine the risk group; however, these results will not be available until your child is 2–4 weeks into therapy. Cytogenetics results can shift your child into a lower or higher risk category. All these risk factors help the healthcare team determine your child's prognosis and will be used to identify the best treatment plan. Further treatment decisions will be made approximately 1 month into treatment when this additional information is known.

HOW IS ALL TREATED?

Most improvements in the treatment of childhood ALL have been made through research and enrollment of children with ALL in clinical trials. During a clinical trial, the best-known standard treatment for a particular cancer is compared with a new experimental treatment. This experimental treatment is believed to be at least as good as, and possibly better than, the standard treatment. Clinical trials allow your healthcare team to determine whether promising new treatments are safe and effective. The goal of a clinical trial is to find out which treatment offers the best chance for cure with the least number of side effects.

Participation in clinical trials is voluntary. Because clinical trials involve research into new treatment plans, all risks cannot be known ahead of time, and unknown side effects may occur. Prior to agreeing to a clinical trial, you will be given paperwork that explains the risks and benefits. Before making a decision about your child's participation in a clinical trial, you should discuss the risks as well as the potential benefits with your child's doctor and treatment team.

Regardless of whether your child is treated in a clinical trial or not, the type and aggression level of treatment is determined by your child's Risk Group, which is based on

- age at diagnosis—Children younger than 1 year or 10 years and older require more aggressive treatment.
- WBC count at diagnosis—Children who have a WBC count higher



than 50,000 require more aggressive treatment.

- type of leukemia—There are different kinds of childhood leukemia; pre-B-cell ALL is the most common and T-cell ALL is less common.
- central nervous system disease—Children with leukemia in their spinal fluid at diagnosis require more aggressive treatment.
- disease outside the bone marrow—Sometimes leukemia cells are seen in different parts of the body (such as the testicles). If your child is found to have disease in other parts of the body (called *extramedullary disease*), the treatment needs to be more aggressive.
- results of cytogenetics and FISH—Leukemia cells can carry certain genetic markers or abnormalities. These markers can affect the type of treatment your child receives. Some types of ALL (such as Philadelphia chromosome ALL [also called BCR-ABL] or mixed lineage leukemia [MLL] gene rearrangement) can be more difficult to treat and require more aggressive therapy. If there are more chromosomes, called *hyperdiploid*, less aggressive chemotherapy may be needed.
- treatment with steroids—Children who receive treatment with steroids before learning that they have leukemia may be placed in a higher-risk group.
- response to treatment—A bone marrow test or a blood test, called *minimal residual disease (MRD)*, will be done on specific days during the first month of treatment. MRD is a test done on bone marrow or blood that determines if microscopic leukemia remains. It can show the prescense of leukemia down to 0.01%. If the MRD is high, more aggressive treatment will be needed. Typically these tests are done after 1 week of chemotherapy and at the end of the first month of treatment.

After the first month of therapy, each child is placed in one of four risk groups.

1. Low Risk

Children between the age of 1 and 9.99 years old with a WBC count lower than 50,000 at diagnosis and **all** of these criteria:

- no testicular disease
- no leukemia in their spinal fluid at diagnosis
- have "good or favorable" chromosome alterations in leukemia cells (these are called ETV6/RUNX1 fusion or trisomy 4,10)
- do not have Down syndrome
- did not receive steroids before diagnosis
- MRD less than 0.01% after first week of chemotherapy **and** at the end of the first month of chemotherapy.

2. Average or Standard Risk

Children younger than 1 year and 10 years or older with a WBC count lower than 50,000 at diagnosis and **all** of these criteria:

- no testicular disease
- very little leukemia in their spinal fluid at diagnosis (called CNS-2)
- have "good or favorable" chromosome alterations in leukemia (ETV6/RUNX1 fusion or trisomy 4,10)
- do not have Down syndrome
- did not receive steroids before diagnosis
- MRD in the first week of treatment of 0.01% or more, and MRD at the end of the first month of treatment of LESS than 0.01%.

AVERAGE RISK WITH DOWN SYNDROME

- children older than 1 year and younger than 10 years who have been diagnosed with Down syndrome
- WBC count lower than 50,000 at diagnosis
- no testicular disease
- no leukemia in their spinal fluid at diagnosis
- no unfavorable cytogenetics such as MLL-rearrangement, hypodiploidy, or Philadelphia chromosome (also called BCR-ABL).

3. High Risk

Children who have **any** of the following factors are considered high risk:

- children older than 1 year and younger than 10 years with a WBC greater than 50,000 at diagnosis
- children 10 years or older, regardless of WBC count
- have testicular disease
- have leukemia in their spinal fluid at diagnosis, called CNS-3
- leukemia cells with certain chromosome abnormalities (such as Philadelphia chromosome ALL [also called BCR-ABL] or MLL gene rearrangement)
- children who were treated with steroids before the diagnosis of ALL was made
- last day of induction therapy MRD greater or equal to 0.01%.

4. Very High Risk

- do not have Down syndrome
- have a chromosome abnormality: iAMP21, MLL rearrangement, hypodiploidy (< 44 chromosomes or DNA index of < 0.81)
- not in remission by the last day of induction, MRD > 0.01%
- unfavorable cytogenetics with Day 29 MRD of > 0.01%.

It is important to determine your child's risk group so the treatment team can determine the chance for a cure. Because ALL is a cancer of the blood-forming cells in the bone marrow, treatment involves the blood system and entire body. All types of B-cell and T-cell ALL are commonly treated with chemotherapy and sometimes with radiation therapy. Your healthcare team will discuss with you the recommended treatment plan based on your child's risk group.

Venous Access Device (VAD)

A venous access device (VAD), sometimes called a central line, is an intravenous (IV) catheter that may be used throughout your child's course of therapy. The purpose of the VAD is to ensure a safe method of delivering chemotherapy (cancer-fighting drugs) and to decrease the discomfort of having numerous needlesticks. It is inserted during surgery when your child is under sedation or general anesthesia either before chemotherapy



begins or within the first month of treatment. It can be used to draw blood for testing purposes and to administer medication, chemotherapy, blood products, and certain types of nutrition. The VAD may remain in your child for the duration of treatment and will be removed when it is no longer needed. There are different types of VADs, such as a port inserted under the skin or a Broviac/Hickman that has a tube, or lumen, which comes out of your child's chest.

Your healthcare team will discuss each type with you and help you choose the best device for your child's treatment. You will be taught how to care for this device at home.

Chemotherapy

Chemotherapy is a cancer treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from growing. Multiple chemotherapy drugs are used to treat both types of ALL (B-cell or T-cell ALL). These medicines are given by mouth; into a vein or VAD, such as a port or Broviac/Hickman (IV); by injection into a muscle (IM); or by a spinal tap into the spinal fluid (called *intrathecal*, or IT). These drugs are used in combination and in a specific sequence called *phases of treatment*. Each phase may use different medications and have different schedules for visiting the hospital or clinic.

Your healthcare team will discuss the medicines used during each phase and their side effects.

INDUCTION

The first phase of treatment is called *induction*. Most children will begin this phase of treatment in the hospital at the time of diagnosis and, depending on their condition, some of this therapy may be given in an outpatient clinic. The goal of the first phase of treatment is to kill all of the leukemia cells and allow normal blood cells to grow again. This is called *remission*. It is important to remember that in remission, signs and symptoms of the cancer have disappeared but leukemia cells may still be hiding in the body.

A bone marrow aspirate and a special blood test called minimal residual disease (MRD) will be performed at certain times during the induction phase to determine how quickly your child is responding to treatment. The goal is to have fewer than 5% leukemia cells or "blasts" in the bone marrow by the 8th day of the induction treatment. A bone marrow aspirate and MRD also will be performed at the end of the induction phase to determine if your child is in remission. Most children with ALL will achieve remission by the end of the induction phase; however, if the bone marrow or MRD does not show that remission has happened after induction, your healthcare team will discuss with you further chemotherapy treatments to achieve remission.

Even though most children achieve a remission by the end of the induction phase, studies confirm that if treatment was stopped after induction, the leukemia cells would return. As a result, therapy continues for 2–3 years after diagnosis.

CONSOLIDATION/INTENSIFICATION

The middle phases of treatment, called *consolidation/intensification*, begin after remission has been achieved. The goals of these phases of treatment are to kill any remaining leukemia cells and to prevent a relapse (i.e., the leukemia cells come back). The intensity of this phase varies considerably based on the risk group in which your child is treated. This phase of therapy may last 6–9 months.

MAINTENANCE

The final phase of treatment is called *maintenance*. This phase continues until there has been 2–3 years of continued remission, depending on the protocol used. Boys receive chemotherapy longer than girls because the

testicles can be a "sanctuary site" where leukemia may hide and then come back. The goal of maintenance is to keep the leukemia in remission. Maintenance is much less intensive than previous phases and consists of oral medicines given at home every day. Intermittent IV and IT (into the cerebral spinal fluid) medications are given in the clinic. Most children may return to school during this phase of treatment. Children begin to feel better and their hair starts to grow back.

Radiation Therapy

If your child has leukemia in the spinal fluid or testicles at diagnosis, or if your child has T-cell ALL, radiation therapy may be a part of his or her treatment. Radiation is typically administered during the middle of treatment. Radiation therapy uses a certain type of energy called *ionizing radiation* to kill leukemia cells by destroying the cells' genetic material. Similar to chemotherapy, radiation therapy damages both cancer cells and normal cells. The goal of radiation therapy is to damage as many cancer cells as possible while limiting harm to healthy cells.

A special team of doctors called *radiation oncologists* will determine the type of radiation your child will receive and how long treatment will continue. First, a process called *simulation* will be used to determine where to aim the radiation. During simulation, the child lies very still on an exam table while the radiation therapist uses a special X-ray machine to determine the exact place on the body where the radiation will be given. The areas to receive radiation are marked with a temporary or permanent marker, tiny dots, or a "tattoo." Sometimes, a special mold is made of foam, plastic, or plaster to keep the child from moving during treatment. In some cases, the therapist also will make shields that cannot be penetrated by radiation to protect organs and tissues near the treatment field. Young children may be given medicines to sedate them during simulation and for each treatment session so that they lie very still. After simulation is complete, the radiation therapy team will meet to decide how much radiation is needed (the dose of radiation), how it should be delivered, and how many treatments the child should have. Your radiation oncologist will discuss the side effects of radiation that can occur during treatment and the side effects that may occur years later, called *late effects*.

WHAT ARE COMMON SIDE EFFECTS FROM TREATMENT?

Chemotherapy drugs have an effect on rapidly dividing cells and, therefore, can unfortunately affect normal cells. When normal cells are damaged, side effects of treatment are seen. Side effects are usually temporary, and the severity of these effects can be decreased with medications. Each child may be affected differently, with some experiencing more side effects than others. There are many types of chemotherapy drugs, each with their own side effects.

Common side effects of chemotherapy medicines include low blood counts, anemia, bleeding, bruising, nausea and vomiting, mucositis (sores in the mouth and throat), alopecia (loss or thinning of hair), darkening of the skin and nails, poor nutrition, diarrhea, or constipation. Hair thinning or loss usually begins around week 3 of treatment and may grow back very short and fall out again between treatments. Medicines such as Zofran (ondansetron) or Kytril (granisetron) are given to help prevent or lessen nausea and vomiting. Low blood counts may be treated with a transfusion of RBCs or platelets. When a child has low blood counts, he or she needs to be carefully monitored for fevers and other signs of illness or infection. Your healthcare team will teach you how to do this at home. Poor nutrition can occur because your child's taste buds change during therapy and food may taste different. Some children do not feel like eating or will eat less than usual. Your dietician can provide tips to help your child.

Many parents notice side effects if their child is taking steroids such as dexamethasone or prednisone. Steroids are used during induction and at various times during the remaining treatment. Side effects from steroids are increased appetite, specific food cravings, joint pain in arms or legs, increased irritability (being "in a bad mood"), and difficulty sleeping. Steroids are important in the treatment of ALL, but their side effects can make it a challenge to care for your child. Discuss these potentially challenging side effects with your healthcare team for help in dealing with steroid treatment.

LONG-TERM FOLLOW-UP

After your child's therapy is completed, your child will have follow-up examinations and medical tests as part of routine cancer care. The first year off therapy is the time when the risk of relapse is highest, so your child will be seen in clinic once a month for a physical exam and blood tests. The frequency of visits to your oncology team will decrease after the first year off therapy. It is important that your child continues to be followed by your oncology team to monitor for side effects from treatment that may be noticed months to years later.

Side effects can be caused by the cancer itself, the treatment, or a combination of both.

After your child has been off therapy for 2–3 years, he or she may be transitioned to a long-term follow-up or survivors' follow-up clinic if one is offered at your hospital. At these clinics, the focus changes from being a "cancer patient" to being a "cancer survivor." Your child may be seen in a long-term follow-up clinic throughout his or her adult life. It is important for children and adults to learn about the treatment they received when they were younger and to commit to necessary long-term follow-up care to ensure their ongoing health.

You may be given a *summary of treatment* from your oncology team that details your child's treatment history (dates and types of chemotherapy, radiation, and surgeries). This is important information that needs to be shared with future healthcare providers. Because the chemotherapy was given when your child was growing, your healthcare team will see your child every year to monitor for long-term side effects from the medicine. Some of these side effects may not be seen until many years after treatment ends. Early detection and prompt care can, in some cases, lessen the severity of residual problems. For example, tests to monitor kidney and liver function may be done yearly, or an echocardiogram (ultrasound of the heart) and electrocardiogram may be done to monitor the heart for damage caused by some of the medicines.

It is important to keep these ongoing appointments with your healthcare team. Late effects of cancer may include physical, emotional, and economic effects. Rarely, a second cancer can result from previous treatment. Psychological and social adjustments or concerns about health insurance, academic achievement, and employment issues can be discussed, and help can be offered in long-term follow-up clinics.

RELAPSE

Unfortunately, despite the best care and treatments, some children may relapse. *Relapse* means the leukemia cells have come back. When a relapse occurs, it is often unexpected and is always unwelcome. The entire family may have the same reactions they had at diagnosis, such as shock and disbelief. You may wonder, "How could

this have happened? Why, if we did everything as instructed, would the disease return?" Sadness and anger also may be the responses to the idea of having to undergo treatment again. Relapse can be even more complicated than the initial diagnosis, in part because the child and family have a better idea of what to expect. While struggling with intense feelings, you are in the position of having to learn about and decide on a new course of treatment. It is important to recognize that relapse, while frightening, does not mean your child will not be cured of the disease. It means that a new approach to treatment must be taken.

BONE MARROW TRANSPLANT (BMT)

A bone marrow transplant (BMT), also known as stem cell transplant, may be one of the treatment options offered to your family if there is a relapse or it may be part of the treatment plan if your child has high- or very high-risk ALL.

The purpose of a BMT is to destroy the relapsed leukemia cells and replace them with normal blood cells. Your child will first receive very high doses of chemotherapy and sometimes radiation therapy to the whole body to destroy all of the blood cells (both the healthy cells and the leukemia cells). Then new bone marrow will be infused, much like a blood transfusion. The new bone marrow may come from different sources and must be a good match for your child. The donor may be related to the child, such as a brother or sister (called a *matched family donor*), or the donor may be someone who is not related to the child (an *unrelated donor*). Many children's cancer hospitals are using umbilical cord blood cells or peripheral blood stem cells as a cell source. BMT can be a difficult process to go through for a child and family. There may be side effects from the chemotherapy, radiation, or medicine used to help the child during and after transplant. Your BMT team will discuss the side effects and risks associated with BMT with you in detail.

HOW CAN I WORK WITH MY CHILD'S HEALTHCARE TEAM?

Many health professionals are involved in the care of children with cancer. Each person serves a valuable role in coordinating their care.

Your child's care requires a team approach. As a parent, you are a major part of the team. Your input is important. You know your child better than anyone else.

It is important to communicate openly with your child's healthcare team. Be sure to question your child's doctor or nurse when there is anything you are not sure about. It helps to write down questions as they come to mind.



IS MY CHILD'S DIET IMPORTANT DURING TREATMENT?

Diet is important during treatment. We know from research that wellnourished children tolerate therapy better and have fewer treatment delays because of illness. Children with leukemia have specific nutritional issues. Because some children experience persistent nausea and vomiting as a result of their illness or the side effects of treatment, proper nutrition is especially important. Your healthcare team will help to prevent and treat your child's nausea. It may be difficult for your child to resume normal eating habits while on therapy, so you will need to be flexible and creative. Your child will better tolerate foods that are appealing to him or



her. Whenever possible, try to choose foods that will provide calories and are high in protein and carbohydrates. Often, numerous, small meals are better tolerated than three larger meals. It also is important to frequently offer your child fluids throughout the day. Your child's liquid intake is an important part of his or her well-being.

Many children with leukemia take steroids at some point during their therapy. It is common to gain weight while taking this medication. Children who take steroids often have an increased appetite and food cravings. Whenever possible, it is helpful to avoid foods that are very salty and to choose healthy food over junk food. It may be helpful to remember that steroid-associated weight gain is usually temporary.

Multivitamins, medicines, and herbs may cause unsafe interactions with chemotherapy and should always be approved by your doctor before you give them to your child.

A dietitian/nutritionist is a part of the healthcare team. He or she is trained in the energy needs of children and also can provide guidance. Your healthcare team will monitor your child's nutritional status, height, and weight during and after therapy. The team will try to prevent problems and suggest changes when there is a nutritional concern.

CAN MY CHILD ATTEND SCHOOL AND OTHER ACTIVITIES DURING TREATMENT?

Your child's ability to attend school and other activities (such as going to the grocery store, shopping mall, movies, or church) will depend on the intensity of the therapy and on his or her response to treatment. Some children tolerate chemotherapy and radiation better than others. Your child may not be able to attend school for extended periods because of the treatments or hospitalizations. In addition, your child may have some limitations related to surgery or treatment. However, it is important that your child keep up with his or her schoolwork. Talk to your healthcare team



and school personnel about arranging services, including help from a home tutor, until your child can return to school. Many pediatric hospitals have programs that enable children to attend school while hospitalized; these programs also can help with home tutoring and other school-related issues. After your child returns to school, the healthcare team will help you arrange for special services that your child may need at school.

ARE MY FEELINGS NORMAL? WHAT CAN I DO ABOUT THEM?

Hearing that your child has cancer is shocking and overwhelming. At first, parents may feel numb and have a hard time believing the diagnosis. Most families find they cannot process all of the information the healthcare team is providing. It is important to know that these feelings are normal and are to be expected.

Many family members feel that they are somehow responsible for their child's disease, or they feel guilty that they were not able to protect their child from this illness or detect it sooner. This disease was not caused or triggered by anything you or anyone did to your child. Initially, leukemia can cause symptoms that are vague or similar to other common illnesses. It may have taken awhile before the diagnosis was made. This is very common.

In addition to the shock and guilt, you and your family may feel anger and sadness. These feelings are normal, and you can expect each family member to express these emotions in different ways and at different times. Talking honestly with each other about feelings, reactions, and questions will help everyone in the family.

It may seem difficult to talk to friends, family, or even the healthcare team, but venting your feelings can help you cope. Your child will benefit if family members continue to show they care through support and communication.

HOW CAN I HELP MY CHILD?

As a parent, you will notice various changes in your child during treatment. These changes or symptoms can make you feel even more helpless. These changes may be because of the leukemia itself or the treatments that follow. Some changes in body appearance and function, such as hair loss, can be temporary; others can be permanent. Additional issues, such as difficulty walking may require therapy and may take some time to improve. All of your feelings about the things your child is going through during treatment must be balanced by remembering that treatment provides an opportunity to cure the disease and allow your child to go on to live a full, meaningful, and productive life.

It is important to reinforce to your child that nothing he or she did or said caused this condition. Likewise, tell

your child that your anger or sad feelings are directed at the disease and not at him or her; this honest approach will help keep your relationship close. Like you, your child will need to share feelings with someone whom he or she can trust. Don't be afraid to ask your child to express his or her feelings, and don't be afraid to explain what is happening and why.

Despite the existence of your child's disease, he or she is still learning and growing. All children, both sick and well, need love, attention, discipline, limits, and the opportunity to try out new skills



and activities. As you begin to learn about your child's new needs, it is important to remember that he or she still has all the rights of any growing, developing child. Do not avoid using direct terms and explanations. Children will tolerate treatment better if they understand it and are allowed to be active decision makers whenever possible. The same is true for parents. Although your child has this disease, he or she should be disciplined in the same manner as other children in the family, or in the way that was typical before the diagnosis. Having structure or a routine also helps you and your child during treatment.

Many parents also say that teaching their child to swallow a pill (instead of having to take liquid medicine that tastes bad even with added flavoring) is a great help. Members of the healthcare team can help with this.

Many children and their families have a difficult time with the changes that happen during treatment. We encourage you to share any concerns you have with your child's healthcare team. There is support and help, and we want to help you.

It is important to note that you know your child better than anyone; if you have concerns about your child or think "something just isn't right," it is very important to notify your healthcare team immediately. A parent's intuition is usually right!

RESOURCES

National Cancer Institute (www.cancer.gov) Clinical Trials registry (www.clinicaltrials.gov) Children's Oncology Group (www.childrensoncologygroup.org) Cure Research (www.cureresearch.com) The National Children's Cancer Society (www.nationalchildrenscancersocity.org)

IMPORTANT PHONE NUMBERS

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