



LEUKEMIA &  
LYMPHOMA  
SOCIETY®

fighting blood cancers

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# Understanding Leukemia



Ray, CML survivor

## A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Our research grants have funded many of today's most promising advances; we are the leading source of free blood cancer information, education and support; and we advocate for blood cancer patients and their families, helping to ensure they have access to quality, affordable and coordinated care.

Since 1954, we have been a driving force behind nearly every treatment breakthrough for blood cancer patients. We have invested more than \$1 billion in research to advance therapies and save lives. Thanks to research and access to better treatments, survival rates for many blood cancer patients have doubled, tripled and even quadrupled.

Yet we are far from done.

Until there is a cure for cancer, we will continue to work hard—to fund new research, to create new patient programs and services, and to share information and resources about blood cancer.

This booklet has information that can help you understand your finances, prepare questions, find answers and resources, and communicate better with members of your healthcare team.

Our vision is that, one day, all people with blood cancers will either be cured or will be able to manage their disease so that they can experience a better quality of life. Today, we hope our expertise, knowledge and resources will make a difference in your journey.



**Louis J. DeGennaro, PhD**

*President and Chief Executive Office*

*The Leukemia & Lymphoma Society*

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This LLS booklet about leukemia is for information only. LLS does not give medical advice or provide medical services.

# Introduction

**This booklet is for anyone interested in learning more about leukemia.** It explains the four main types of leukemia, how leukemia is diagnosed, general methods of treatment, some side effects and how The Leukemia & Lymphoma Society (LLS) can help.

The progress that has been made in treating leukemia gives patients and caregivers more hope than ever before. Treatments may include drug therapy, monoclonal antibody therapy, stem cell transplantation and, for some patients, radiation therapy.

*Understanding Leukemia* is for people with leukemia and others who want basic information about these diseases. Many people find that it helps to know the questions to ask about choosing a specialist and about treatment. There are suggested questions to ask your doctor and a list of other healthcare question guides you can print at [www.LLS.org/whattoask](http://www.LLS.org/whattoask), or contact our Information Specialists for copies.

Some words in *Understanding Leukemia* may be new to you. Check *Medical Terms* beginning on page 22. Or, call our Information Specialists at (800) 955-4572.

## Want more information?



You can view, print or order the free LLS publications *The ALL Guide: Information for Patients and Caregivers*, *The AML Guide: Information for Patients and Caregivers*, *The CLL Guide: Information for Patients and Caregivers*, and *The CML Guide: Information for Patients and Caregivers* for more information. Go to [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for copies.

# Here to Help

*Understanding Leukemia* will help you talk to your doctor about tests and treatment. Members of your healthcare team will answer your questions and give support and any needed referrals. Let your doctor know if you want a professional healthcare interpreter who speaks your native language or uses sign language. Many times, this is a free service.

The news that you have leukemia may be a shock to you and your loved ones. You may feel sad, depressed or afraid. Keep in mind that

- Many people are better able to cope once their treatment plan is established and they can look forward to recovery.
- The outlook for people with leukemia continues to improve. New approaches to therapy are being studied in clinical trials for patients of all ages and at every stage of treatment.

**LLS Has Ways to Help.** Treatment for leukemia will affect your daily life for a time. You may want to ask friends or family members to help you

- Get information
- Take care of chores.

We want you to know that LLS offers free information and patient services for individuals and families touched by blood cancers.

**Information Specialists.** Our Information Specialists are master's level professionals. They provide up-to-date blood cancer information. You can call to speak with an Information Specialist Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can also email [infocenter@LLS.org](mailto:infocenter@LLS.org) or chat online at [www.LLS.org](http://www.LLS.org).

**Clinical Trials.** Our Information Specialists help patients work with their doctors to find out about specific clinical trials. You can also use **TrialCheck**<sup>®</sup>, an online clinical-trial search service supported by LLS.

TrialCheck offers patients and caregivers immediate access to listings of blood cancer clinical trials. You can reach this online service by visiting [www.LLS.org/clinicaltrials](http://www.LLS.org/clinicaltrials).

**Language Services.** Free language services are available for calls with our Information Specialists.

**Free Materials and Información en Español.** LLS has free patient education and support booklets in English and Spanish. You can order these materials by phone at (800) 955-4572. You can also read or print the booklets, or order free print versions, at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter).

**Co-pay Assistance Program.** This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Check [www.LLS.org/copay](http://www.LLS.org/copay) or call (877) 557-2672 to speak to a *Co-Pay Assistance Program* specialist for more eligibility information.

**Chapter Programs and Services.** LLS chapter offices around the United States and Canada offer support and education. Your chapter can arrange for you to speak to another person living with a similar type of leukemia through the *Patti Robinson Kaufmann First Connection Program*. The *Patient Financial Aid* program offers a limited amount of financial aid for qualified patients. Find your chapter by calling (800) 955-4572 or by visiting [www.LLS.org](http://www.LLS.org).

**Telephone/Web Education Programs.** LLS provides free telephone and web education programs by experts for patients and caregivers. For more information contact our Information Specialists or visit [www.LLS.org/programs](http://www.LLS.org/programs).

**School Reentry.** *The Trish Greene Back to School Program for Children With Cancer* helps doctors, nurses, parents and school personnel work together for a smooth return to school for children with cancer. For more information contact your LLS chapter or call our Information Specialists at (800) 955-4572.

**Reach Out.** You and your loved ones can reach out to others for support. For example:

- LLS offers online Blood Cancer Discussion Boards and live online chats at [www.LLS.org/getinfo](http://www.LLS.org/getinfo).
- Local or Internet support groups and blogs can give support.
- You may get to know other people living with cancer. These friendships provide support.

**Information for Veterans.** Veterans with certain types of leukemia who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information call the Department of Veterans Affairs at (800) 749-8387 or visit [www.publichealth.va.gov/exposures/agentorange](http://www.publichealth.va.gov/exposures/agentorange).

### **Suggestions From Other People Living With Cancer**

- Get information about choosing a cancer specialist or treatment center.
- Talk with family and friends about how you feel and how they can help you.
- Find out what your insurance covers.
- Find out if financial assistance is available.
- Learn about the most current tests and treatments for your type of leukemia.
- Talk openly with the doctor about your fears or concerns.
- Tell your doctor if you have any side effects of treatment.
- Contact your doctor if you have fatigue, fever, pain or sleep problems.
- Get medical advice if you have changes in mood or feelings of sadness or depression.

**We'd Like to Hear From You.** We hope this booklet helps you. Please tell us what you think at [www.LLS.org/publicationfeedback](http://www.LLS.org/publicationfeedback). Click on **LLS Disease & Treatment Publications—Survey for Patients, Family and Friends.**

# Part 1 – Understanding Leukemia

The information on this page about normal blood and marrow may help you understand the information in the rest of *Understanding Leukemia*.

## About Marrow, Blood and Blood Cells

**Marrow** is the spongy center inside of bones where blood cells are made.

**Blood cells** are made in the marrow. They begin as stem cells. Stem cells become red cells, white cells and platelets in the marrow. Then the red cells, white cells and platelets enter the blood.

**Platelets** form plugs that help stop bleeding at the site of an injury.

**Red cells** carry oxygen around the body. When the number of red cells is below normal, the condition is called **anemia**. Anemia may make you feel tired or short of breath. It may make the skin look pale.

**White cells** fight infection in the body. There are two major types of white cells: germ-eating cells (neutrophils and monocytes) and infection-fighting **lymphocytes** (B cells, T cells and natural killer [NK] cells).

**Plasma** is the liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.



## Normal Blood Cell Count Fast Facts

The ranges of blood cell counts below are for adults. They may be a little different from lab to lab and for children and teens.

### Red blood cell (RBC) count

- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

### Hematocrit (the part of the blood made up of red cells)

- Men: 42% to 50%
- Women: 36% to 45%

### Hemoglobin (amount of the red cell pigment that carries oxygen)

- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

### Platelet count

- 150,000 to 450,000 platelets per microliter of blood

### White blood cell (WBC) count

- 4,500 to 11,000 white cells per microliter of blood

### Differential (also called diff)

- Shows the part of the blood made up of different types of white cells
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood.

## What is Leukemia?

**Leukemia** is the general term for some different types of blood cancer. There are **four main types** of leukemia called:

**Acute lymphoblastic (lymphocytic) leukemia (ALL)**

**Acute myeloid (myelogenous) leukemia (AML)**

**Chronic lymphocytic leukemia (CLL)**

**Chronic myeloid (myelogenous) leukemia (CML).**

It is important to know that patients are affected and treated differently for each type of leukemia. These four types of leukemia do have one thing in common – they begin in a cell in the bone marrow. The cell undergoes a change and becomes a type of leukemia cell.

The marrow has two main jobs. The first job is to form myeloid cells. Myeloid leukemia can begin in these cells. The second job is to form lymphocytes, which are a part of the immune system. Lymphocytic leukemia can arise in these cells.

The leukemia is called **lymphocytic** or **lymphoblastic** if the cancerous change takes place in a type of marrow cell that forms **lymphocytes**. The leukemia is called **myelogenous** or **myeloid** if the cell change takes place in a type of marrow cell that normally goes on to form red cells, some kinds of white cells and platelets.

For each type of leukemia, patients are affected and treated differently.

ALL and AML (acute leukemias) are each composed of young cells, known as **lymphoblasts** or **myeloblasts**. These cells are sometimes called **blasts**. Acute leukemias progress rapidly without treatment.

CLL and CML have few or no blast cells. CLL and CML often progress slowly compared to acute leukemias, even without immediate treatment.

## How Does Leukemia Develop?

Doctors do not know the causes of most cases of leukemia. They do know that once the marrow cell undergoes a leukemic change, the leukemia cells may grow and survive better than normal cells. Over time, the leukemia cells crowd out or suppress the development of normal cells.

The rate at which leukemia progresses and how the cells replace the normal blood and marrow cells are different with each type of leukemia.

**Acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL).** In these diseases, the original acute leukemia cell goes on to form about a trillion more leukemia cells. These cells are described as **nonfunctional** because they do not work like normal cells. They also crowd out the normal cells in the marrow. This causes a decrease in the number of new normal cells made in the marrow. This further results in low red cell counts (anemia), low platelet counts (bleeding risk) and low neutrophil counts (infection risk).

**Chronic myeloid leukemia (CML).** The leukemia cell that starts this disease makes blood cells (red cells, white cells and platelets) that function almost like normal cells. The number of red cells is usually less than normal, resulting in anemia. But many white cells and sometimes many platelets are still made. Even though the white cells are nearly normal in how they work, their counts are high and continue to rise. This can cause serious problems if the patient does not get treatment. If untreated, the white cell count can rise so high that blood flow slows down and anemia becomes severe.

**Chronic lymphocytic leukemia (CLL).** The leukemia cell that starts this disease makes too many lymphocytes that do not function. These cells replace normal cells in the marrow and lymph nodes. They interfere with the work of normal lymphocytes, which weakens the patient's immune response. The high number of leukemia cells in the marrow may crowd out normal blood-forming cells and lead to a low red cell count (anemia). A very high number of leukemia cells building up in the marrow also can lead to low white cell (neutrophil) and platelet counts.

Unlike the other three types of leukemia, some patients with CLL may have disease that does not progress for a long time. Some people with CLL have such slight changes that they remain in good health and do not need treatment for long periods of time. Other patients require treatment at the time of diagnosis or soon after.

### Estimated number of people in the United States newly diagnosed each year:

AML about 12,950

CLL about 14,570

CML about 5,150

ALL about 5,730

About 274,930 people in the United States are living with, or in remission from, leukemia.

## Who's at Risk?

People can get leukemia at any age. It is most common in people over age 60. The most common types in adults are AML and CLL. Each year, about 3,811 children develop leukemia. ALL is the most common form of leukemia in children.

The term **risk factor** is used to describe something that may increase the chance that a person will develop leukemia.

For most types of leukemia, the risk factors and possible causes are not known. For AML, specific risk factors have been found, but most people with AML do not have these risk factors.

Most people who have these risk factors do not get leukemia – and most people with leukemia do not have these risk factors.

Some risk factors for AML are:

- Some types of chemotherapies
- Down syndrome and some other genetic diseases
- Chronic exposure to benzene. The majority of benzene in the environment comes from petroleum products, however, half of the personal exposure is from cigarette smoke
- Radiation therapy used to treat cancer.

Exposure to high doses of radiation therapy is also a risk factor for ALL and CML. In CLL, while it is not common, some families have more than one blood relative with the disease. Doctors are studying why some families have a higher rate of CLL. Other possible risk factors for the four types of leukemia are continually under study. Leukemia is not contagious (catching).

## Signs and Symptoms

Some signs or symptoms of leukemia are similar to other more common and less severe illnesses. Specific blood tests and bone marrow tests are needed to make a diagnosis.

Signs and symptoms vary based on the type of leukemia. For acute leukemia, they include:

- Tiredness or no energy
- Shortness of breath during physical activity
- Pale skin
- Mild fever or night sweats
- Slow healing of cuts and excess bleeding
- Black-and-blue marks (bruises) for no clear reason
- Pinhead-size red spots under the skin
- Aches in bones or joints (for example, knees, hips or shoulders)
- Low white cell counts, especially monocytes or neutrophils.

People with CLL or CML may not have any symptoms. Some patients learn they have CLL or CML after a blood test as part of a regular checkup.

Sometimes, a person with CLL may notice enlarged lymph nodes in the neck, armpit or groin. The person may feel tired or short of breath (from anemia) or have frequent infections if the CLL is more severe. In these cases, a blood test may show an increase in the lymphocyte count.

CML signs and symptoms tend to develop slowly. People with CML may feel tired and short of breath while doing everyday activities. They may also have an enlarged spleen (leading to a “dragging” feeling on the upper left side of the belly), night sweats and weight loss.

**Each type of leukemia may have other symptoms or signs that prompt a person to get a medical checkup.**

Any person troubled by symptoms such as a lasting, low-grade fever, unexplained weight loss, tiredness or shortness of breath should see a doctor.

## Diagnosis

A **CBC (complete blood count)** is used to diagnose leukemia. A CBC is a test that is also used to diagnose and manage many other diseases. This blood test may show high or low levels of white cells and show leukemia cells in the blood. Sometimes, platelet counts and red cell counts are low. Bone marrow tests (aspiration and biopsy) are often done to confirm the diagnosis and to look for chromosome abnormalities. These tests identify the leukemia cell-type.

Chromosomes are parts of each cell that carry genes. Genes give the instructions that tell each cell what to do.

A complete blood exam and a number of other tests are used to diagnose the type of leukemia. These tests can be repeated after treatment begins to measure how well the treatment is working.

### How Are Blood and Bone Marrow Tests Done?

#### Blood tests

| Usually a small amount of blood is taken from the person's arm with a needle. The blood is collected in tubes and sent to a lab.

#### Bone marrow aspiration

| A liquid sample of cells is taken from the marrow through a needle. The cells are then looked at under a microscope.

#### Bone marrow biopsy

| A very small amount of bone filled with marrow cells is removed through a needle. The cells are then looked at under a microscope.

Each main type of leukemia also has different **subtypes**. In other words, patients with the same main type of leukemia may have different forms of the disease. A patient's age, general health and subtype may play a role in determining the best treatment plan. Blood tests and bone marrow tests are used to identify AML, ALL, CML or CLL subtypes.

## Tracking Your Leukemia Tests

These tips may help you to save time and to know more about your health.

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports and treatment records. Organize test reports by date.
- Find out if and when follow-up tests are needed.
- Mark appointments that are coming up on your calendar.

### Want more information?



You can view, print or order the free LLS publication *Understanding Lab and Imaging Tests* to learn more about lab tests and what to expect at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for a copy.

## Part 2 – Treatment

### Choosing a Specialist

Choose a doctor who specializes in treating leukemia and knows about the most up-to-date treatments. This type of specialist is usually called a **hematologist/oncologist**. Or your local cancer specialist can work with a leukemia specialist.

### Want more information?



You can view, print or order the free LLS publication *Choosing a Blood Cancer Specialist or Treatment Center* at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for a copy.



## Ways to Find a Leukemia Specialist

- Ask your primary care doctor.
- Contact your community cancer center.
- Call your local medical society.
- Reach out to doctor and/or health plan referral services.
- Call LLS for a list of cancer centers or go to [www.LLS.org/cancercenters](http://www.LLS.org/cancercenters).
- Use online doctor-finder resources, such as
  - The American Medical Association's (AMA) "DoctorFinder"
  - The American Society of Hematology's (ASH) "Find a Hematologist."

## Ask Your Doctor

Talk with the doctor and ask questions about how he or she plans to treat your leukemia. This will help you to be actively involved in your care and to make decisions.

It may be helpful to write down the answers to your questions and review them later. You may want to have a caregiver, a family member or friend with you when you talk to the doctor. This person can listen, take notes and offer support. Some people like to record information from the doctor and then listen to the recording later on.

People with leukemia who are unsure about their treatment options are encouraged to get a second opinion.

### Want more information?



For a list of healthcare question guides about treatment, second opinions and other topics that you can print, go to [www.LLS.org/whattoask](http://www.LLS.org/whattoask) or contact our Information Specialists for copies.

## Treatment

It is important to get medical care at a center where doctors are experienced in treating patients with leukemia. The aim of leukemia treatment is to bring about a complete remission. This means that after treatment, there is no sign of the disease and the patient returns to good health. Today, more and more leukemia patients are in complete remission at least five years after treatment.

**Acute Leukemia.** Treatment for patients with acute leukemia may include chemotherapy, stem cell transplantation or new approaches under study (clinical trials). Speak to your doctor to find out what treatment is best for you.

Patients with an acute leukemia (acute lymphoblastic leukemia [ALL] and acute myeloid leukemia [AML]) need to start treatment soon after diagnosis. Usually, they begin treatment with chemotherapy, which is often given in the hospital. The first part of treatment is called **induction therapy**. More inpatient treatment is usually needed even after a patient is in remission. This is called **postremission therapy** and consists of **consolidation (intensification) therapy** and in some cases **maintenance therapy**. This part of treatment may include chemotherapy with or without stem cell transplantation (sometimes called **bone marrow transplantation**).

**Chronic Myeloid Leukemia (CML).** Patients with CML need treatment soon after diagnosis. There are three drugs approved for newly diagnosed patients. These drugs are **imatinib mesylate (Gleevec®)**,

**dasatinib (Sprycel®)** or **nilotinib (Tasigna®)**. If one of these drugs is not effective, one of the other drugs can be tried. All three of these drugs are taken by mouth. Gleevec, Sprycel and Tasigna do not cure CML. But they keep CML under control for many patients for as long as they take it. Allogeneic stem cell transplantation is another treatment option that is only done if CML is not responding as expected to drug therapy.

**Chronic Lymphocytic Leukemia (CLL).** Some CLL patients do not need treatment for long periods of time after diagnosis, sometimes called **watch and wait**. Patients who need treatment may receive chemotherapy or monoclonal antibody therapy alone or in combination. Allogeneic stem cell transplantation is a treatment option for certain patients, but usually not as the first choice of therapy.

**Want more information?**



You can view, print or order the free LLS publications *Blood and Marrow Stem Cell Transplantation*, *The ALL Guide: Information for Patients and Caregivers*, *The AML Guide: Information for Patients and Caregivers*, *The CLL Guide: Information for Patients and Caregivers* and *The CML Guide: Information for Patients and Caregivers* at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for copies.

## Part 3 – Clinical Trials

There are new treatments under study for leukemia patients of all ages. New treatments are studied in clinical trials. These trials are also used to study new uses for approved drugs or treatments. For example, changing the amount of the drug or giving the drug along with another type of treatment might be more effective. Some clinical trials combine drugs for leukemia in new sequences or dosages.

There are clinical trials for

- Newly diagnosed leukemia patients
- Patients who do not get a good response to treatment
- Patients who relapse after treatment
- Patients who continue treatment after remission (maintenance).

A carefully conducted clinical trial may provide the best available therapy.

Ask your doctor if treatment in a clinical trial is right for you. You can also call our Information Specialists for information about clinical trials, or use our free clinical trial service at [www.LLS.org/clinicaltrials](http://www.LLS.org/clinicaltrials).

**Want more information?**



You can view, print or order the free LLS publication *Knowing All Your Treatment Options* at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for a copy.

## Part 4 – Side Effects and Follow-Up Care

### Side Effects of Leukemia Treatment

The term **side effect** is used to describe the way that treatment affects healthy cells.

**People react to treatments in different ways.** Sometimes they have mild side effects. Many treatment side effects go away when treatment ends or become less noticeable over time. Most can be handled without the need to stop the drug. Other side effects may be serious and lasting.

For example, people who have side effects from monoclonal antibody therapy may experience the side effects while getting the IV treatment. Side effects from chemotherapy, such as nausea or changes to normal blood cells, may occur for a period of time after the treatment.

Talk to your doctor about the possible side effects and long-term effects of your drugs or other therapies, such as radiation therapy. You can also call an LLS Information Specialist.

**Acute leukemias (acute lymphoblastic leukemia [ALL] and acute myeloid leukemia [AML]).** Common side effects **may** include

- Changes to blood counts
- Mouth sores
- Nausea
- Vomiting
- Diarrhea
- Hair loss
- Rash
- Fever.

**Chronic lymphocytic leukemia (CLL).** Common side effects **may** include

- Extreme tiredness
- Hair loss
- Changes to blood counts
- Upset stomach
- Mouth sores
- Diarrhea.

**Chronic myeloid leukemia (CML).** Common side effects from tyrosine kinase inhibitor therapy such as Gleevec **may** include

- Changes to blood counts
- Diarrhea
- Muscle cramps and joint aches
- Nausea
- Swelling or fluid retention.

**Want more information?**



You can view, print or order the free LLS publication *Understanding Drug Therapy and Managing Side Effects* at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for a copy.

## Follow-Up Care

AML, ALL, CML and CLL patients who are in remission need to see their doctors regularly for exams and blood tests. Bone marrow tests may be needed from time to time. The doctor may recommend longer periods of time between follow-up visits if a patient continues to be disease free. Each type of leukemia may be followed differently. Speak to your doctor to find the best care plan for you.

Patients and caregivers should talk with their doctors about long-term and late effects of cancer treatment. Cancer-related fatigue is one common long-term effect.

### Want more information?



You can view, print or order the free LLS publications *Long-Term and Late Effects of Treatment in Adults*, *Long-Term and Late Effects of Treatment for Childhood Leukemia and Lymphoma* and *Learning & Living With Cancer* at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter) or contact our Information Specialists for copies.

## Take Care of Yourself

- Keep all appointments with the doctor. People with leukemia need medical follow-up after they have completed treatment. It is important to see if more therapy is needed.
- Discuss how you feel with the doctor at each visit.
- People with leukemia may have more infections. Follow the doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contact your doctor if you are feeling tired or have a fever or any other symptoms.
- Do not smoke. People who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings. People with leukemia have a risk for a second cancer, including melanoma, sarcoma, colorectal cancer, lung cancer, basal cell cancer, squamous cell skin cancer or myeloma.
- See your primary care doctor to keep up with other healthcare needs.

- Talk with family and friends about how you feel. When family and friends have information about leukemia and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. For example, if you feel sad or depressed every day for a two-week period, seek help. Depression is an illness. It should be treated even when a person is being treated for leukemia. Treatment for depression has benefits for people living with cancer.

## Medical Terms

**Antibiotics.** Drugs that are used to treat infections caused by bacteria or fungi. Penicillin is one type of antibiotic.

**Antibodies.** Proteins that help to fight infection in the body.

**Bone marrow aspiration.** A procedure to remove and examine marrow cells to see if they are normal. Bone marrow aspirate is almost always done with bone marrow biopsy. The test may be done in the doctor's office or in a hospital.

**Bone marrow biopsy.** A procedure to remove and examine marrow cells to see if they are normal. A very small amount of bone filled with marrow cells is taken from the body and the cells are looked at under a microscope. The sample is usually taken from the patient's hip (pelvic) bone.

**Central line.** Special tubing the doctor puts into a large vein in the upper chest or forearm (called a **PICC line**) to prepare a patient for chemotherapy treatment. The central line is used to give the patient chemotherapy drugs and blood cells, and to remove blood samples. Also called **indwelling catheter**. Some of these sit entirely under the skin and do not have any tubes that show above the skin. These are called implantable venous access ports.



**Chemotherapy.** Treatment with drugs or medicines that kill or damage cancer cells.

**Chromosomes.** Parts of each cell that carry genes. Genes give instructions that tell each cell what to do. The number or shape of chromosomes may be changed in blood cancer cells.

**Clinical trials.** Careful studies done by doctors to test new drugs or treatments, or new uses for approved drugs or treatments. The goal of clinical trials for blood cancers is to improve treatment and quality of life and to find cures.

**Consolidation therapy.** Added treatment given to a cancer patient after the disease is in remission. It usually includes chemotherapy drugs not used during induction therapy. Also called **intensification therapy**.

**Cytogenetic analysis.** The examination of the chromosomes of leukemia cells to give doctors information about how to treat patients. Cell samples can be taken from blood or marrow.

**Donor immune cells.** The donated stem cells that a patient receives from a stem cell transplant. These can help him or her make new blood cells and new immune cells.

**Drug resistance.** When a drug used to treat a patient's disease does not work or stops working.

**FDA.** Short name for the **US Food and Drug Administration**. Part of the FDA's job is to assure the safety and security of drugs, medical devices and the US food supply.

**FISH.** The short name for **fluorescence in situ hybridization**, a test to measure the presence of a specific chromosome or gene in cells. The results of this test can be used to plan treatment and to measure the results of treatment.

**Hematologist.** A doctor who treats blood cell diseases.

**Hemoglobin.** The part of the red cell that carries oxygen.

**Immune system.** Cells and proteins in the body that defend it against infection. Lymphocytes, lymph nodes and the spleen are parts of the body's immune system.

**Immunity.** The ability to resist infection.

**Immunoglobulins.** Proteins that fight infection.

**Immunophenotyping.** A lab test that can be used to find out if the patient's lymphocytic leukemia cells are B cells or T cells.

**Immunotherapy.** The treatments that are used to boost or suppress the body's immune system, such as monoclonal antibody therapy. Other immunotherapies are being studied for leukemia treatment, such as vaccines. These vaccines would not prevent leukemia, but would help the immune system's attack against leukemia cells.

**Induction therapy.** The first part of chemotherapy treatment for acute leukemia.

**Leukapheresis.** A process in which extra white cells are removed by a machine.

**Lumbar puncture (spinal tap).** A medical procedure in which a small amount of the fluid that surrounds the brain and spinal cord is removed and examined. Also called a **spinal tap**.

**Lymph nodes.** Small bean-shaped organs around the body that are part of the body's immune system.

**Lymphocyte.** A type of white cell that is part of the immune system and fights infection.

**Monoclonal antibody therapy.** Immune proteins made in the laboratory. This type of therapy targets and kills specific cancer cells. It does not cause many of the side effects of chemotherapy.

**Oncologist.** A doctor who treats patients who have cancer.

**Pathologist.** A doctor who identifies disease by studying cells and tissues under a microscope.

**Postremission therapy.** The treatment given to some leukemia patients after induction therapy. Postremission therapy may have two parts: consolidation (or intensification) and maintenance.

**Radiation therapy.** Treatment with x-rays or other high-energy rays.

**Refractory disease.** Disease that has not responded to initial therapy. Refractory disease may be disease that is getting worse or staying the same (stable disease).

**Relapse or recurrence.** When disease comes back after it has been successfully treated.

**Remission.** No sign of the disease and/or a period of time when the disease is not causing any health problems.

**Spinal tap.** See lumbar puncture.

**Spleen.** An organ found on the left side of the body, near the stomach. It contains lymphocytes and removes red cells that no longer work from the blood.

**Tyrosine kinase inhibitor (TKI).** A drug that blocks cell growth. Gleevec®, Sprycel® and Tasigna® are TKIs that are used to treat CML.









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is today®**

fighting blood cancers

## REACH OUT TO OUR **INFORMATION SPECIALISTS**

**The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.**

Our team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 am to 9 pm (ET).

### **Co-Pay Assistance**

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

**For more information, call 877.557.2672 or visit [www.LLS.org/copay](http://www.LLS.org/copay).**



**For a complete directory of our patient services programs, contact us at**

**800.955.4572 or [www.LLS.org](http://www.LLS.org)**

*(Callers may request a language interpreter.)*



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For more information, please  
contact our Information Specialists  
800.955.4572 (Language interpreters  
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[www.LLS.org](http://www.LLS.org)



or:

**National Office**

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**Our Mission:**

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.

