



**The Leukemia &  
Lymphoma Society®**

*Fighting Blood Cancers*

# Understanding Leukemia

LEUKEMIA

LYMPHOMA

MYELOMA



# 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, and how The Leukemia & Lymphoma Society 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.

**More information about each type of leukemia and specific treatments is in the Society's free booklets, including:**

*Acute Lymphocytic Leukemia: A Guide for Patients and Families*

*Acute Myelogenous Leukemia: A Guide for Patients and Families*

*Chronic Lymphocytic Leukemia: A Guide for Patients and Families*

*Chronic Myelogenous Leukemia: A Guide for Patients and Families*

**Other free materials from the Society are listed on pages 17 and 18.**

**1** **Questions? Contact an Information Specialist at The Leukemia & Lymphoma Society at [www.LLS.org](http://www.LLS.org) or 800-955-4572.**

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**D**efinitions for **Medical Terms** that may be new to readers begin on page 19.

This booklet from The Leukemia & Lymphoma Society is for general information only. Additional disease and treatment-specific information appears in several of the Society's other free publications. The Society does not give medical advice or medical services.

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# What Is Leukemia?

“Leukemia” is the general term for **four different types** of blood cancer called:

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

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

**Chronic lymphocytic leukemia (CLL)**

**Chronic myelogenous leukemia (CML)**

It is important to know that how patients are affected and treated are not the same 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.

**M**arrow is the spongy center of bones where blood cells and lymphocytes are formed. Blood cells begin as “stem” cells. The different types of cells made in the marrow are red cells, platelets, lymphocytes and several other types of white cells. These cells leave the marrow and enter the blood once they are formed.

The **marrow is really two organs** in one. The first is the blood cell-forming organ. This is the site where myelogenous leukemia begins. The second is the **lymphocyte-forming organ** and is a part of the immune system. It is the site where lymphocytic leukemia begins.

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.

The ways in which patients are affected and how they are treated are different for each type of leukemia.

“**Acute lymphocytic leukemia**” and “**acute myelogenous leukemia**” are each composed of young cells, known as “lymphoblasts” or “myeloblasts.” These cells are sometimes called “blasts.” **Acute leukemias progress rapidly without treatment.**

“**Chronic**” leukemias have few or no blast cells. “**Chronic lymphocytic leukemia**” and “**chronic myelogenous leukemia**” usually progress slowly compared to acute leukemias.

# 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, it multiplies into many cells. These **leukemia cells grow and survive better than normal cells** and, over time, they crowd out normal cells.

**N**ormal stem cells in the marrow form three main cell-types. **Red cells** carry oxygen to all the tissues of the body, such as the heart, lung and brain; **platelets** prevent bleeding and form “plugs” that help stop bleeding after an injury; and **white cells** fight infection in the body.

There are two **major types of white cells**: germ-ingesting cells (**neutrophils** and **monocytes**) and **lymphocytes**, which provide **immunity** to infection.

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

In **acute myelogenous leukemia (AML)** and **acute lymphocytic leukemia (ALL)**, 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; in turn, this causes a decrease in the number of new normal cells made in the marrow. This further results in low red cell counts (anemia).

In **chronic myelogenous leukemia (CML)**, the leukemia cell that starts the 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.

**H**aving too few red cells is called “anemia.” It can make a person look pale and feel tired and short of breath.

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**In chronic lymphocytic leukemia (CLL)**, the leukemia cell that starts the 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. Most patients require treatment at the time of diagnosis or soon after.

**E**stimated number of people in the United States diagnosed each year:

AML about 12,000

CLL about 10,000

CML about 4,500

ALL about 4,000

About 208,000 people in the United States are living with 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 3,500 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.

**M**ost people who have these risk factors do not get leukemia – and most people with leukemia do not have these risk factors.

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Some risk factors for **AML** are:

- Certain chemotherapies used for lymphoma or other types of cancer
- Down syndrome and some other genetic diseases
- Chronic exposure to benzene (such as in the workplace) that exceeds federally approved safety limits
- Radiation therapy used to treat other types of cancer
- Tobacco smoke.

Exposure to high doses of radiation therapy is also a risk factor for **ALL** and **CML**. 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 and go to the doctor. 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.**

**T**he best advice for any person troubled by symptoms such as a lasting, low-grade fever, unexplained weight loss, tiredness or shortness of breath is to see a healthcare provider.

# Diagnosis

A **CBC** (complete blood count) is used to diagnose leukemia. The 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.

**C**hromosomes 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.

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.

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# Treatment

**T**reatment and outcomes depend on the type and subtype of leukemia. Please see the Society's free disease and treatment-specific booklets for details about ALL, AML, CLL and CML.

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.

Patients with an **acute leukemia** need to start treatment right away. Usually, they begin treatment with chemotherapy 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 **“consolidation”** or **“post induction”** therapy. This part of treatment may include chemotherapy with or without stem cell transplantation (sometimes called “bone marrow transplantation”).

Patients with CML need to begin treatment once they are diagnosed. They usually begin treatment with imatinib mesylate (Gleevec®). This drug is taken by mouth. Gleevec® does not cure CML. But it keeps CML under control for many patients for as long as they take it. Other drugs such as dasatinib (Sprycel®) are used for certain patients instead of Gleevec®.

**Allogeneic stem cell transplantation** is the only treatment that can cure CML at this time. This treatment is most successful in younger patients. But patients up to 60 years of age who have a matched donor may be considered for this treatment. Allogeneic transplantation can be a high-risk procedure. Studies are under way to see whether CML patients have better long term outcomes with drug therapy or with transplantation.

Some **CLL** patients do not need treatment for long periods of time after diagnosis. 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.

**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.

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

The Society's free fact sheet, *Long-Term and Late Effects of Treatment for Blood Cancers*, has more information on this topic. The Society's free booklet, *Learning & Living With Cancer*, has more information for caregivers of children with cancer.

### **New Treatment Methods**

New cancer treatments are under study in clinical trials to help a growing number of patients achieve remission or be cured of their disease. Cancer clinical trials are studies to test new and better ways to:

- Diagnose and treat leukemia and other cancers
- Prevent or relieve treatment side effects
- Help prevent a return of disease
- Improve comfort and quality of life

The Society's free booklet, *Understanding Clinical Trials for Blood Cancers*, has more information about clinical trials.



# Social and Emotional Effects of Leukemia

Hearing the words, “you have leukemia,” may make a person feel as if life has changed completely in an instant. It may help to know that after diagnosis, many people with leukemia do survive and live many good, quality years. Most people with leukemia are able to cope with what at first may seem too hard to accept. This usually takes time. Knowing more about the disease and its treatment may make it easier to cope. Patients may first want to focus on learning about their type of leukemia and its treatment. They can then look ahead to remission and recovery.

Patients should ask their healthcare team for help and guidance, not only for medical concerns, but also for any emotional issues relating to the disease and its treatment. This includes the special needs of children or a family member or friend with leukemia.

Making treatment choices and finding the time and money for medical care are stressful. Contact the Society or ask the healthcare team for guidance and referrals to other sources of help.

To order free booklets, contact **The Leukemia & Lymphoma Society** at [www.LLS.org](http://www.LLS.org) or **800-955-4572**.

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# We're Here to Help

The Leukemia & Lymphoma Society provides education and support for the public and cancer treatment professionals through its **local chapters** and **Information Resource Center**.

Local **chapter programs** include one-to-one peer support and support groups; financial help with medication, transportation and procedure costs; and education programs.

Visit the Society's Web site at [www.LLS.org](http://www.LLS.org) or contact the Society's Information Resource Center at (800) 955-4572 to locate a chapter in your area, order free publications or speak directly to an Information Specialist. Information Specialists provide accurate and up-to-date disease and treatment information. Information specialists also help with clinical trial searches for patients, family members and healthcare professionals.

**The Leukemia & Lymphoma Society's free materials include:**

*Acute Lymphocytic Leukemia*

*Acute Myelogenous Leukemia*

*Chronic Lymphocytic Leukemia*

*Chronic Myelogenous Leukemia*

*Choosing and Communicating with a Cancer Specialist and  
Choosing a Treatment Facility (fact sheet)*

*Blood and Marrow Stem Cell Transplantation*

*Blood Transfusion*

*Each New Day – Ideas for Coping with Leukemia, Lymphoma  
or Myeloma*

*Fatigue (fact sheet)*

*Financial Health Matters*

*Integrative Medicine & Complementary and Alternative  
Therapies as Part of Blood Cancer Care (fact sheet)*

*Long-Term and Late Effects of Treatment for Blood Cancers  
(fact sheet)*

*Touching Lives – A Directory of Patient Services Programs*

*Understanding Blood Counts (fact sheet)*

*Understanding Clinical Trials for Blood Cancers*

*Understanding Drug Therapy and Managing Side Effects*

## **Materials for or about children**

*Emotional Aspects of Childhood Blood Cancers*

*Learning & Living With Cancer*

*The Stem Cell Transplant Coloring Book*

To order free booklets, contact **The Leukemia & Lymphoma Society**  
at **[www.LLS.org](http://www.LLS.org)** or **800-955-4572**.

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# Medical Terms

## **Allogeneic stem cell transplantation**

A treatment that uses donor stem cells to restore a patient's marrow and blood cells. First, the patient is given "conditioning therapy" (high-dose chemotherapy or high-dose chemotherapy with total body radiation) to treat the leukemia and to "turn off" the patient's immune system so that the donor stems will not be rejected. A type of transplant called a "nonmyeloablative" transplant (or "mini" transplant) is under study. It uses lower doses of conditioning therapy and may be safer, especially for older patients.

## **Antibiotics**

Drugs that are used to treat infections. Penicillin is one type of antibiotic.

## **Antibodies**

Proteins that help to fight infection in the body.

## **Autologous stem cell infusion**

Blood or marrow stem cells are taken from a patient in remission. The cells are stored and then reinfused as soon as conditioning with chemotherapy and/or radiotherapy is completed.

## Medical Terms

### **Bone marrow aspiration**

A test done that shows the cell-type and certain abnormalities by looking at proteins on the cell's surface. It is done by removing a sample of fluid and cells (the aspirate) from the marrow through a special needle. The sample is usually taken from the patient's hip bone. Bone marrow aspirate is almost always done with bone marrow biopsy. The tests may be done in the doctor's office or in a hospital.

### **Bone marrow biopsy**

A test that shows chromosome and gene abnormalities and how much disease is in the marrow. It is done by removing a very small amount of bone filled with marrow cells. The sample is usually taken from the patient's hip bone.

### **Central line**

Special tubing put into a large vein in the patient's upper chest to give the chemotherapy drugs and blood cells, and to remove blood samples. Also called an "indwelling catheter."

### **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.

# Medical Terms

## **Clinical trials**

Studies that use volunteers to test new drugs, treatments or new uses for approved drugs or treatments.

## **Consolidation therapy (Post induction therapy)**

Added treatment given to a patient even after acute leukemia is in remission.

## **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.

## **Cytokines**

Natural substances made by cells that can also be made in the lab. “Growth factor cytokines” are used to help restore normal blood cells during treatment. In the future, “immune cell cytokines” may be used to treat leukemia.

## **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 does not work or stops working.

# Medical Terms

## **FDA**

Short name for the U.S. Food and Drug Administration. The FDA looks at the results of drug studies and determines if a drug is safe and effective.

## **FISH test**

“Fluorescence *in situ* hybridization” (FISH) is a test used to check for chromosome abnormalities.

## **Hematologist**

A doctor who treats blood cell diseases.

## **Hemoglobin**

A substance in red blood cells that carries oxygen.

## **Immune system**

Cells and proteins that defend the body 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.

# Medical Terms

## **Immunotherapy**

The term for treatments that can boost the body's immune system such as monoclonal antibody therapy. Other immunotherapies are being studied for leukemia treatment such as vaccines that 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 blood cell. Lymphocytes help fight infection.



# Medical Terms

## **Monoclonal antibody**

A type of drug that targets cancer cells.

## **Oncologist**

A doctor who treats patients with cancer.

## **Pathologist**

A doctor who identifies disease by studying tissues under a microscope.

## **Radiation therapy**

Treatment with X-rays or other high-energy rays.

## **Refractory disease**

Disease did not respond to therapy.

## **Relapse or recurrence**

A return of disease after it has been successfully treated.

## **Remission**

No sign of the disease and/or a long time span when the disease is not causing any health problems for the patient.

## **Spleen**

An organ found on the left side of the body, near the stomach. It contains lymphocytes and cleans worn-out cells from the blood.



# Call Our Information Resource Center

The Society's Information Resource Center (IRC) provides patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma. Our information specialists – master's level oncology professionals – are available by phone (800.955.4572) Monday through Friday, 9 am to 6 pm (ET); via email ([infocenter@LLS.org](mailto:infocenter@LLS.org)); or chat online at [www.LLS.org](http://www.LLS.org) (click on "Live Help").

Call 800.955.4572 for a complete directory of our patient services programs.

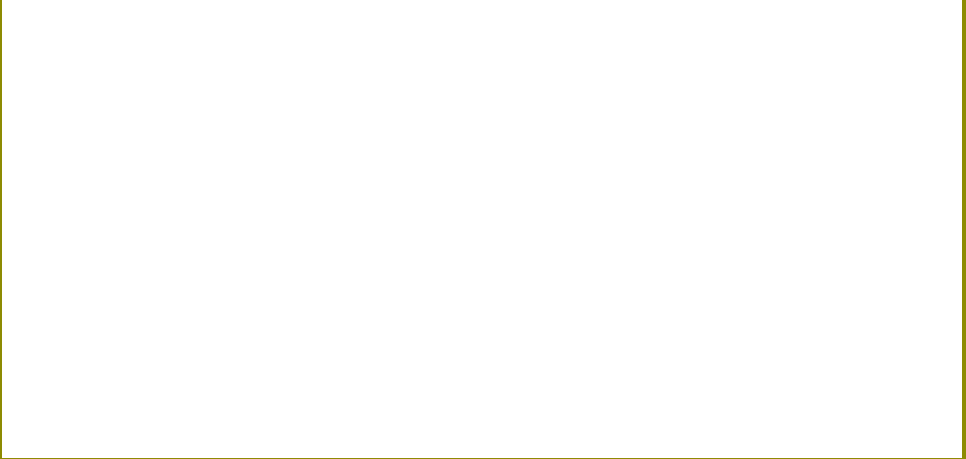


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For more information, please contact:



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[www.LLS.org](http://www.LLS.org)

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

The Society is a nonprofit organization that relies on the generosity of corporate and individual contributions to advance its mission.



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