For more information, please contact:

or:

Home Office
1311 Mamaroneck Avenue, Suite 310
White Plains, NY 10605
Information Resource Center (IRC) 800.955.4572
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.

The Leukemia & Lymphoma Society®

Fighting Blood Cancers

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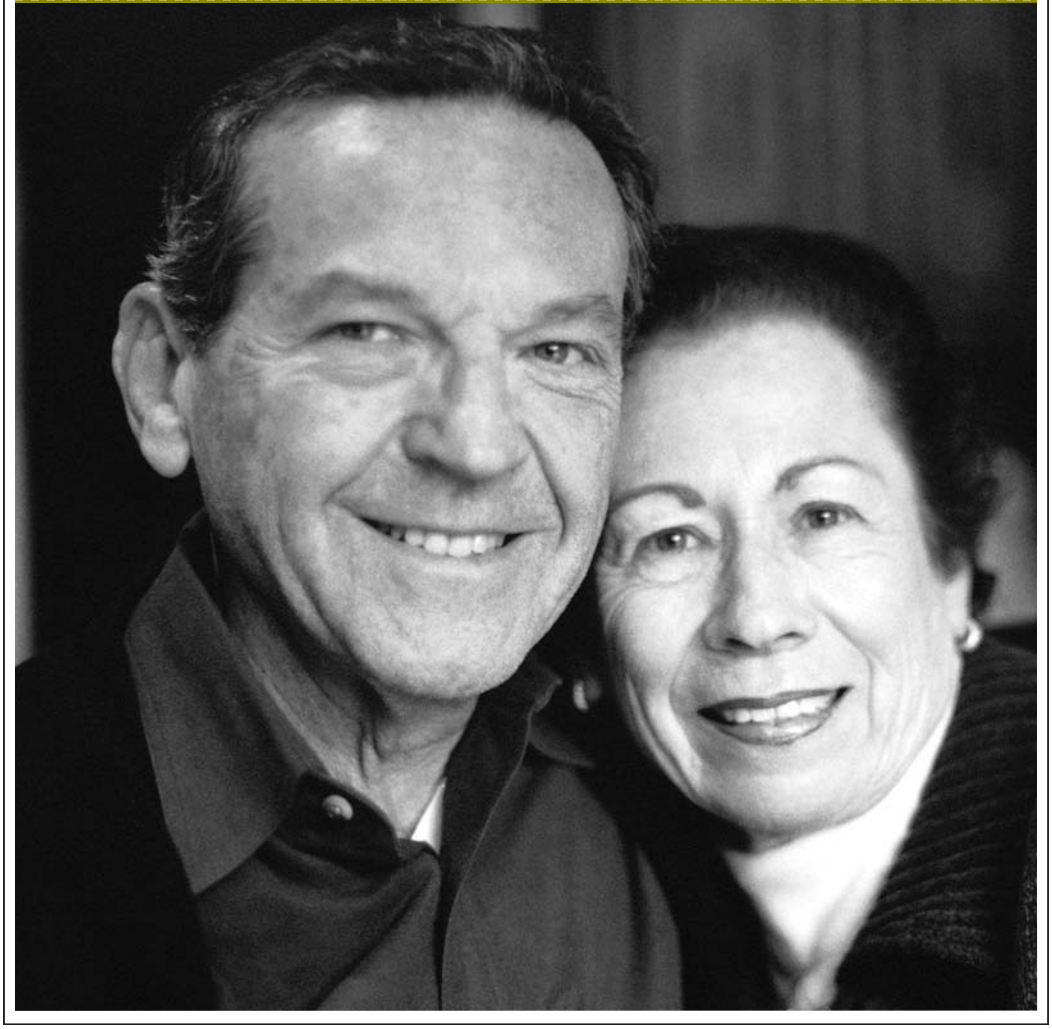
The Leukemia & Lymphoma Society®
Fighting Blood Cancers

CLL: A Guide for Patients and Families

LEUKEMIA | LYMPHOMA | MYELOMA

CHRONIC LYMPHOCYTIC LEUKEMIA



Many people feel well and live for many years with chronic lymphocytic leukemia (CLL.)

About **74,000**
People in the U.S. are living with CLL
•
About **8,000**
People in the U.S. learn they have CLL each year.

There is no cure for CLL. But today there are many treatments. And doctors are looking for new ways to treat CLL. Their goals are to add years of good health to the lives of people with CLL and to find a cure.

This booklet is for CLL patients and their families. It will help you learn about CLL and how it is treated.

Some words in the booklet may be new to you. Check **Medical Terms** at the back of this booklet. Or call **The Leukemia & Lymphoma Society** at **1-800-955-4572**.

Part 1 answers the questions:

- What is CLL?
- Who gets CLL?
- How does the doctor find CLL?

Part 2 answers the questions:

- What is "watch and wait?"
- What are the treatments for CLL?
- How do I get more information?

Part 1 - Understanding CLL

Chronic lymphocytic leukemia (CLL) is a type of blood cancer.
CLL is a common form of leukemia in adults. More people are living with CLL than any other type of leukemia.

Doctors do not know why some people get CLL and others do not.
Most people with CLL are at least 50 years old. A few people with CLL are less than 45 years old. In certain families, more than one blood relative has gotten CLL. This does not usually happen. But it is being studied so doctors can learn more about why some families have more CLL.

CLL starts with a change to a single cell called a lymphocyte.
A lymphocyte is a type of white blood cell.

Doctors do not know what causes a healthy cell to change to a chronic lymphocytic leukemia cell (CLL cell).
Healthy lymphocytes help fight infection. CLL cells do not.

Many people with CLL have low-risk CLL.
Low-risk CLL patients often have no **symptoms** in the early stages of CLL. A **symptom** is a change in the body that you see or feel. Low-risk CLL patients have little or no change to their daily routines for many years.

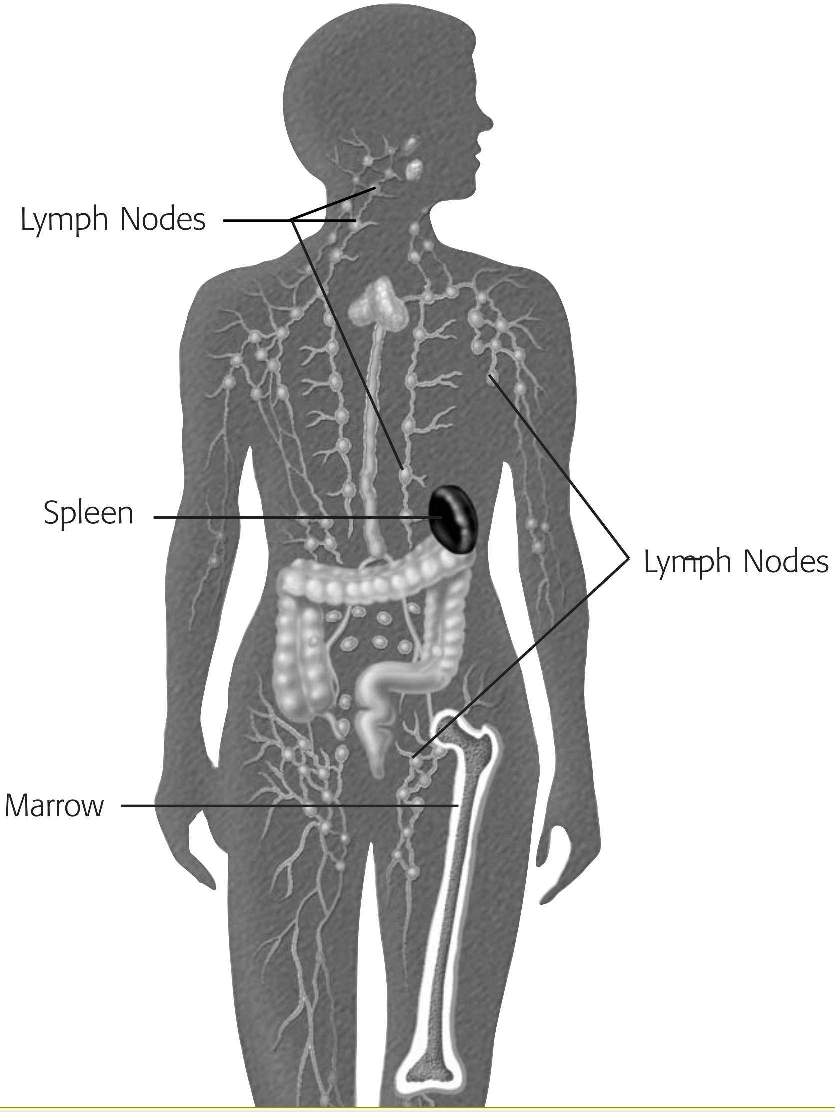
Many CLL patients say they learned about their CLL after a routine check-up.
When an enlarged **lymph node** or an enlarged **spleen** is found during a physical exam, or when a routine **blood test** shows a higher than normal number of **lymphocytes** a doctor will do a **lab test** for more information.

The **lymphocytes**, the **lymph nodes** and the **spleen** are part of the body's **immune system**.

Some Parts of the Immune System

The normal immune system gives protection all around the body.

There are about 600 lymph nodes located throughout the body.



Doctors use lab tests to look at cells in blood and marrow.

A test called **flow cytometry** is used to find out if a patient has CLL. This test is also called **immunophenotyping**. Flow cytometry shows if CLL is causing the high number of lymphocytes in the blood. Flow cytometry can also show if the CLL began with a B cell or a T cell. B cell is most common.

Other lab tests are done if flow cytometry shows the patient has CLL. A **cytogenetic analysis** looks to see if there are changes in the **chromosomes** of the CLL cells.

FISH (fluorescence *in situ* hybridization) is another test that is used to check for chromosome changes. After CLL treatment begins it can be used to see if treatment is working. This is done by measuring the number of cells with abnormal chromosomes that remain after treatment.

> Each cell has **chromosomes** that carry **genes**. Genes give the instructions that tell each cell what to do.

A **bone marrow biopsy** is used to look at the amount and pattern of CLL cells in the marrow. A bone marrow biopsy is not always done for low-risk CLL patients. In patients with more advanced CLL a bone marrow biopsy is usually done as a **baseline**. The results from the **baseline** are compared to a repeat bone marrow biopsy after treatment. This is one way to tell how the patient is doing after treatment.

Doctors also may check the blood for **immunoglobulins** (gamma globulins.) Immunoglobulins are proteins that help the body fight infection. CLL patients may not have enough of these proteins. With more advanced CLL, low levels of immunoglobulins may be a cause of repeated infections.

About Blood Cells

All blood cells begin as **stem cells**. Stem cells are made in **marrow**, the spongy center inside the bones.

Stem cells become **red cells**, **white cells** and **platelets** in the marrow and then enter the blood.

Red cells carry oxygen around the body.

Anemia – the number of red cells is below normal. Anemia can make you tired, pale or short of breath.

White cells fight infection in the body. A neutrophil is a type of white cell that fights infection.

Neutropenia – the number of neutrophils is below normal.

Platelets prevent bleeding and form plugs that help stop bleeding after injury to a blood vessel.

Thrombocytopenia – the number of platelets is below normal.

Part 2 – Treatment

A person with low-risk CLL will need repeat visits to the doctor.

The doctor will check for any health changes.

At each office visit the doctor will:

- Talk to the patient about how he or she feels.
- Examine the patient.
- Order lab tests.

It is hard to tell ahead of time when a patient will need treatment. Some doctors and patients call this, "watch and wait."

The results of exams and lab tests over time will help the doctor advise the patient about when to start treatment.

"Watch and wait" is hard for many people to get used to.

For low-risk CLL patients it is best not to start treatment as long as the patient feels well.

About 6 months to a year after finding CLL, the doctor has a better idea about the patient's type of CLL and treatment plans.

Each patient should talk to the doctor about CLL and future plans for treatment. One patient's CLL may not be the same as another patient's.

Some people have a faster growing form of CLL. They will need treatment sooner.

There are a number of ways the doctor gets information about treating the patient's CLL.

All the ways are important – together they give a complete picture.

- One way is for the patient to tell the doctor how he or she feels.
- Another is for the doctor to examine the patient and look for changes in the body, especially the lymph nodes and spleen.
- The doctor also compares lab test results from one office visit to the next to look for any changes.

A doctor may advise a patient with one or more of these signs to begin treatment:

- The number of CLL cells is much higher than it was.
- The number of normal cells is much lower than it was.
- The lymph nodes have become larger.
- The spleen has become larger.

A patient with any or all of these signs may start to feel too tired for normal daily activities.

About CLL Cells

CLL cells live longer than normal lymphocytes.

Over time, CLL cells crowd healthy blood cells in the blood, lymph nodes and marrow.

As the number of CLL cells grows, some patients may have enlarged **lymph nodes** or an enlarged **spleen**, or both. This is caused by CLL cells piling up in the lymph nodes and spleen.

CLL patients may start to feel less energy when they have fewer healthy red blood cells and more CLL cells.

There is no cure for CLL. Treatment goals are to:

Choosing when to **begin** treatment and the **type** of **treatment** to have are big decisions.

- Slow the piling up of CLL cells.
- Keep patients feeling well enough to carry on their day-to-day activities.
- Protect patients from infection.

Many doctors use a staging system to help plan a CLL patient's treatment.
The stages are 0–4. To "stage" a patient's CLL a doctor thinks about:

- The patient's number of CLL cells.
- If the patient's lymph nodes, spleen or liver are enlarged.
- If the patient is anemic (red cells less than normal).
- If the patient has a very low platelet count.

Questions? Talk to an **Information Specialist** at **The Leukemia & Lymphoma Society 800-955-4572** or **www.LLS.org** .

Treatment options for CLL include:

Chemotherapy is treatment with drugs that kill or damage cancer cells. Some drugs are given by mouth. Other drugs are given through a vein by placing a small needle in the arm (called an IV). Two or more drugs may be used together.

Immunotherapy is treatment that uses the body's own defenses to fight CLL and other diseases. **Monoclonal antibody therapy** is a type of immunotherapy. Monoclonal antibodies may be used as a first treatment. Or they may be used to treat small amounts of CLL that remain after chemotherapy. This gives patients a better chance to stay free of CLL cells for a longer time.

Alemtuzumab (Campath®) is a monoclonal antibody approved to treat medium and high-risk CLL. **Rituximab (Rituxan®)** is approved to treat some lymphomas. Rituxan® is used in **clinical trials** to treat CLL. Clinical trials are studies that use volunteers to test new treatments. The goal of research is to find better ways to treat CLL and other diseases.

CLL Drugs and Monoclonal Antibodies

Name of Drug	Brand Name
chlorambucil	Leukeran
cladribine	Leustatin
cyclophosphamide	Cytoxan, Neosar
doxorubicin	Adriamycin, Rubex
fludarabine	Fludara
prednisone	Deltasone
vincristine	Oncovin, Vincasar
alemtuzumab	Campath
rituximab	Rituxan

Doctors are testing new drugs and new combinations of drugs to treat CLL. Doctors are also testing new ways to use drugs that are already approved. For example, changing the dose or giving the drug along with another type of treatment might be better.

To learn more about clinical trials, ask your doctor if a clinical trial might help you. You can also call the Society for general information about clinical trials.

Stem Cell Transplantation (SCT) is a treatment to restore a patient's marrow. Stem cells are taken from a donor and given to the patient. A few CLL patients may be treated with SCT. The treatment is not used for older patients or low-risk patients. A patient who might be treated with SCT usually:

- Has a fast growing form of CLL.
- Is younger than age 50.
- Has a relative who is a "match" to donate stem cells.

Doctors are working to make SCT safer. In the future, more CLL patients may have this treatment. A mini-transplant treatment is under study.

To learn more about SCT, speak to your doctor. You can also call the Society.

Radiation therapy is treatment with X-rays or other high-energy rays. Radiation therapy is not a common treatment for CLL. It may be used if a CLL patient has an enlarged lymph node, spleen or other organ that is blocking a normal body function.

Splenectomy is a type of operation used on a very small number of CLL patients. The spleen is an organ on the left side of the body, near the stomach. Its job is to clean worn out cells from the blood. If the spleen gets filled with too many CLL cells it may cause discomfort or pressure. Also, a large spleen may lower blood cell counts to dangerous levels. Then it might be removed by surgery. Only some patients benefit from removal of the spleen. Removing the spleen can cause complications. For this reason, it would only be done if other treatments were not an option.

CLL patients should talk with the doctor about side effects before they begin treatment.

The **main effect** of drug treatment for CLL is to kill CLL cells. The term **side effect** is used to describe how drugs affect healthy cells. Patients react to CLL treatment in different ways. Sometimes there are no side effects. Sometimes side effects are mild and last only a short time. Other side effects may be serious and last a long time. Most side effects go away when patients complete treatment.

Some Side Effects

- Low red cell count (anemia)
- Extreme tiredness
- Infection
- Upset stomach
- Hair loss

What should I ask the doctor?

Talk with the doctor about CLL and how the doctor plans to treat the disease. This will help you to know more about your disease and treatment. It will help you to be involved and make decisions.

Here are some questions to ask.

- What do my blood tests show? How do my results compare to "normal"?
- When will I need to take these tests?
- When do you think I will need treatment?
- Why do I need to wait to begin treatment?
- What kind of treatment do you think I will need?
- Is there a clinical trial that might help me?
- What side effects should I expect from treatment?
- What can I do to help deal with side effects?
- What do you think will happen with my CLL in the future?
- Should I change my daily routine?
- How many CLL patients do you have?

It may be helpful to write down the answers to your questions and review them later. You may want to bring a family member or friend with you to the doctor. This person can listen, take notes, and offer support. Some patients find it easier to tape record information from the doctor and listen to the tape at home.

CLL patients should talk with their family and friends about how they feel. They can share what they know about the disease. When family and friends know about CLL they may worry less.

The Leukemia & Lymphoma Society is here to help.

The Leukemia & Lymphoma Society has chapters around the nation. The Society's chapters offer support groups and also can arrange for a CLL patient to talk with another person who has CLL. **To find the Society's chapter in your area, call (800) 955-4572.** Or go to the Society's Web site at **www.LLS.org** .

The Leukemia & Lymphoma Society (LLS) has free booklets.

Chronic Lymphocytic Leukemia gives more detailed information about CLL for patients and their families.

Financial Health Matters is about financial aid, insurance and ways to manage money.

Coping with Survival is about support for people living with adult leukemia.

Understanding Drug Therapy and Managing Side Effects is about many cancer drugs and common side effects.

Choosing and Communicating with a Cancer Specialist and *Choosing a Treatment Facility* are fact sheets that may help you plan your healthcare.

To order these and other booklets call the toll-free line at (800) 955-4572 or visit the Web site at **www.LLS.org** .

Medical Terms

Chemotherapy
Treatment with drugs or medicines to kill cancer cells.

Immunoglobulins
These are proteins that fight infection.

Immune System
Cells and proteins that defend the body against infection. Lymphocytes, lymph nodes and the spleen are some parts of the immune system.

Leukemia
Leukemia is a cancer of the marrow and blood.

Lymph Nodes
Small bean-shaped organs around the body that are part of the body’s immune system.

Lymphocyte
Type of white blood cell. Lymphocytes help fight infection.

Marrow
Spongy material in the center of bones where blood cells are made.

Monoclonal Antibodies
A type of drug that can locate and bind to cancer cells.

Platelet
Type of blood cell that helps prevent bleeding by causing plugs to form.

Medical Terms

Red Cells
Blood cells that carry oxygen to all parts of the body. In healthy people, red blood cells make up almost half of the blood.

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.

Splenectomy
An operation to remove the spleen.

Stem Cells
Cells made in marrow that make red cells, white cells, and platelets.

White Cells
White cells help the body fight infection.

Notes