

The CLL Guide:

Information for Patients and Caregivers



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A six-word narrative about living with blood cancer from patients in our LLS Community

Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at
www.LLS.org/Community

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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INTRODUCTION

Chronic lymphocytic leukemia (CLL) is a type of blood cancer. It is the most common type of leukemia in Western countries. CLL generally affects seniors, with more than 83 percent of patients older than age 65.

Advances in the treatment of CLL have resulted in improved remission rates and quality of life for patients. The number of CLL patients who are in remission increases each year.

- About 21,250 people in the United States were expected to be diagnosed with CLL in 2021.
- About 181,666 people in the United States are living with or are in remission from CLL as of 2017.

This is a hopeful time for people with CLL. In recent years, new therapies have been approved and other new treatments for CLL are being studied in clinical trials.

New treatments may have been approved since this book was printed. Check www.LLS.org/DrugUpdates or call **(800) 955-4572**.

Visit www.LLS.org/booklets to view, download or order all LLS free publications mentioned in this booklet.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Chronic Lymphocytic Leukemia* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Feedback. Visit www.LLS.org/PublicationFeedback to make suggestions about this booklet.

Overview of This Section

- Blood cells start off as stem cells, which are made in bone marrow, inside bones. Stem cells normally develop into healthy red blood cells, white blood cells or platelets, and then leave the bone marrow and enter the bloodstream.
- The lymphatic system is part of the immune system, which helps protect the body from infection and disease.
- A lymphocyte is a type of white blood cell.
- Chronic lymphocytic leukemia (CLL) starts with a change (mutation) to a single lymphocyte in the bone marrow.
- CLL is typically diagnosed with blood tests.

About Bone Marrow, Blood and Blood Cells

The general descriptions below may help you understand the information in the rest of this Guide.

Bone marrow is the spongy center located inside the bones where blood cells are made.

Blood cells begin as stem cells in the bone marrow. Stem cells grow and mature into different types of blood cells: red blood cells, white blood cells and platelets. After they have matured, the red blood cells, white blood cells and platelets enter the bloodstream.

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

White blood cells fight infection in the body. There are two major types of white blood cells, lymphocytes and germ-eating cells:

1. Lymphocytes are infection-fighting cells. The three types are:

- B cells
- T cells
- NK cells

2. Germ-eating cells ingest bacteria and viruses. The two types are:

- Neutrophils
- Monocytes

Platelets help stop bleeding by clumping together (**clotting**) at the site of an injury. **Thrombocytopenia** is a condition in which there is a lower-than-normal number of platelets in the blood. It may cause easy bruising and excessive bleeding from cuts and wounds.

Plasma is the liquid part of the blood, not including the blood cells. Although mostly water, plasma 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 (PLAT C)

- 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)

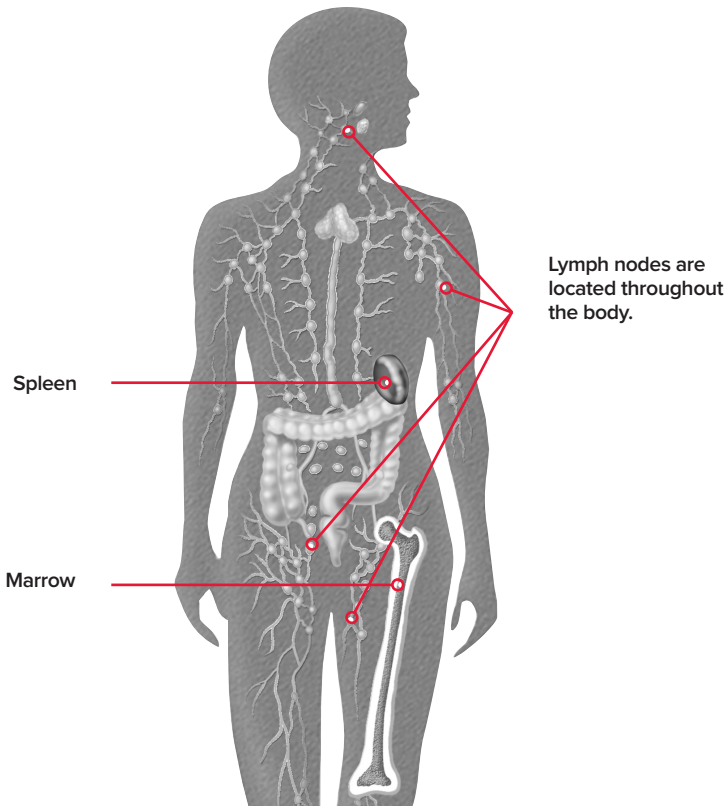
- Shows the part of the blood made up of different types of white cells
- Counts the types of white cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils)
 - Normal adult white blood cell count: neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood

About the Lymphatic System

The lymphatic system is part of the immune system that helps protect the body from infection and disease. The lymphatic system includes

- **Bone marrow and lymphocytes.** Bone marrow is located inside the bones and produces white blood cells called lymphocytes that fight infection.
- **Lymph nodes.** Lymph nodes are small, bean-sized collections of lymphocytes. There are about 600 lymph nodes—in the neck, armpits, chest, abdomen, groin and other body parts. Lymphatic vessels connect the lymph nodes and contain **lymph**, a fluid that carries lymphocytes.
- **The spleen** is an organ on the left side of the body near the stomach. It contains lymphocytes, and removes old or damaged blood cells.

Some Parts of the Immune System



About CLL

Leukemia is the general term for a number of different types of blood cancer. CLL is one of the four main types of leukemia.

CLL is a type of cancer that begins in the bone marrow. It starts with a change (mutation) to a lymphocyte (a type of white blood cell). This abnormal leukemia cell multiplies uncontrollably. Over time, leukemia cells can build up in the blood, bone marrow, spleen and lymph nodes.

Causes and Risk Factors of CLL. Doctors do not know what causes most cases of CLL. There is no way to prevent CLL, and you cannot catch CLL from someone else.

A “risk factor” is something that increases your chance of getting a disease. There are few known risk factors for CLL.

- Some studies have associated exposure to Agent Orange, an herbicide used during the Vietnam War, with an increased risk of CLL. (See *Information for Veterans* on page 34).
- Some studies suggest that exposure to benzene at work increases the risk of CLL.
- Genetic factors likely play a role in the development of CLL, as some families have more than one affected family member with the disease.

Children do not get CLL. The disease generally affects older people. The median age at diagnosis is 72 years.

Signs and Symptoms. Many signs and symptoms of CLL are the same signs and symptoms that are caused by other illnesses. A **sign** is a change in the body that the doctor sees in an exam or a test result. A **symptom** is a change in the body that the patient can see or feel. Most people with signs and symptoms of CLL do not have CLL, but may have another disease or condition.

Some people with CLL have no symptoms. They may find out they have CLL after a routine blood test during a regular medical checkup shows certain changes in the blood. CLL symptoms often develop slowly over time. These symptoms may include:

- Extreme tiredness, lack of energy
- Shortness of breath
- Enlarged lymph nodes (particularly in the neck)
- Low-grade fever
- Unexplained weight loss

- Night sweats
- Feelings of fullness (due to an enlarged spleen or liver)
- Infection of the skin, lungs or sinuses

Diagnosis

It is important for patients to receive the right diagnosis. A diagnosis of CLL is usually based on blood tests.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

- What kind of testing will be done to diagnose my disease and to monitor my treatment?
- How long does it take to get the results?
- How will I get the test results?
- How often will testing be needed?
- Where will the testing be done?

Complete Blood Cell Count and Examination. A test called a **complete blood count (CBC)** is used to count the number of red blood cells, white blood cells and platelets in a blood sample. A diagnosis of CLL is usually based on the results of blood cell counts and an examination of blood cells. People with CLL will have high numbers of lymphocytes in the blood. There may also be low red blood cell counts and low platelet counts.

Immunophenotyping. This test can diagnose specific types of leukemia and lymphoma by detecting certain proteins on a cell's surface. The sample of cells comes from a blood or bone marrow test. The test can be used to see if the lymphocytes in a blood sample contain CLL cells.

Quantitative Immunoglobulin Test. Doctors check the immunoglobulin level in the blood. Immunoglobulins are proteins that help the body fight infection. People with CLL may have low levels of immunoglobulins. A low immunoglobulin level may be the cause of repeated infections.

Bone Marrow Aspiration and Biopsy. Bone marrow aspiration and biopsy are procedures in which two small samples of bone marrow (liquid and bone) are removed from the hip bone using special needles and sent to the laboratory for examination. These bone marrow tests are not usually needed to make a CLL diagnosis, but they may be helpful before treatment begins. The results of these tests serve as a baseline used later to see whether the treatment is working. Bone marrow aspiration and biopsy are usually done at the same visit.

Visit www.LLS.org/3D and click on "Bone Marrow Biopsy and Aspiration" to view an interactive 3D image which will help you visualize and better understand the bone marrow aspiration and biopsy procedures.

How Are the Blood and Bone Marrow Tests Done?

Blood Test — A small amount of blood is taken from the patient's arm with a needle. The blood is collected in tubes and sent to a lab.

Bone Marrow Aspiration — The removal of a sample of fluid with cells from the bone marrow.

Bone Marrow Biopsy — A very small amount of bone filled with marrow cells is taken from the body.

Both bone marrow tests are done with a special needle. Some patients are awake for the procedure. They get medication first to numb the part of the body that will be used to take the sample of cells. Some patients are given a drug that makes them sleep during this procedure. The sample of cells is usually taken from the patient's hip bone.

Blood and marrow tests may be done in the doctor's office or in a hospital. Bone marrow aspiration and biopsy are almost always done at the same visit.

Bone Marrow Aspiration and Biopsy

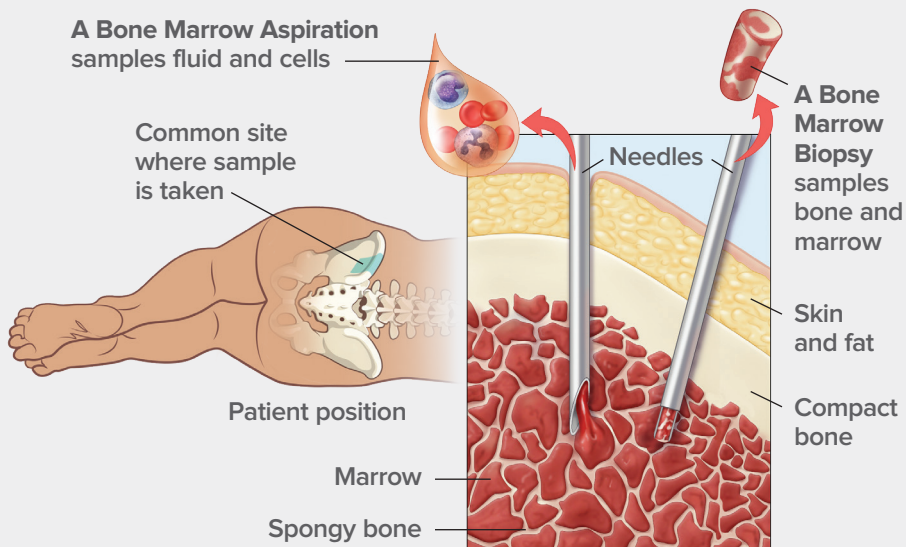


Figure 1. Left: The place on the back of the patient's pelvic bone where a bone marrow aspiration or biopsy is done. **Right:** Where one needle goes into bone marrow to get a liquid sample for aspiration and the other needle goes inside the bone for a bone biopsy. The needles are different sizes.

Fluorescence In Situ Hybridization (FISH). This test is used to see if there are changes to the chromosomes of the CLL cells and can be done with samples of either blood or bone marrow cells. Every cell in the body has chromosomes that contain genes. Genes give the instructions that tell the cell what to do. About 80 percent of CLL patients who are tested using the FISH test have chromosome abnormalities. In CLL cells, the chromosomes that usually have defects are chromosomes 11, 12, 13 and 17. The FISH test may give doctors information that will help them plan treatment.

Karyotyping. This test provides a snapshot of the chromosomes by pairing and arranging all the chromosomes of a cell in order. It can provide more complete information about chromosomes than the FISH test. A blood or bone marrow sample from the patient can be used.

DNA Sequencing. This test uses blood or bone marrow samples to look for mutations in the genes of CLL cells. Certain mutations are markers that can help doctors identify patients who have higher-risk disease.

Tracking Your CLL Tests

These tips may help you save time and learn 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 in a folder or binder.
 - Organize test reports in order by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

WANT MORE INFORMATION?



You can view, print or order the free LLS book ***Understanding Lab and Imaging Tests*** at www.LLS.org/booklets, or contact our Information Specialists for a copy.

PART 2 TREATING CLL

Overview of This Section

- People with CLL should choose a CLL specialist. These doctors are called **hematologist-oncologists**.
- Ask questions about your treatment choices and do not be afraid to be involved in making decisions about your own care. See the *Treatment and Follow-Up Care Question Guide* on pages 45-48.
- Once a diagnosis of CLL is confirmed, your doctor will use information about your cancer to assign a stage. Staging helps the doctor to predict the outcome of your cancer, and it is also used to determine when to start treatment.
- Not all CLL patients need to start treatment right away. Starting treatment is based on symptoms of CLL, test results and the cancer stage.
- Current therapies do not offer patients a cure for CLL, but there are treatments that have the potential to give patients longer remissions and a better quality of life.

Finding the Right Doctor

Choose a doctor who specializes in treating leukemia and knows about the most up-to-date treatments. This type of specialist is called a **hematologist-oncologist**. A hematologist is a doctor who has special training in disorders of the blood, and an oncologist is a doctor who has special training in cancer. Your local cancer specialist may work with a hematologist-oncologist. Always check to see if the doctor's affiliated hospital or your chosen hospital is covered under your health insurance plan.

How to Find a Leukemia Specialist

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center and ask for a recommendation.
- Reach out to doctor and/or health insurance plan referral services.
- Call an LLS Information Specialist at **(800) 955-4572**.
- Use online doctor-finder resources, such as
 - The American Medical Association's (AMA) "DoctorFinder" online at **<https://doctorfinder.ama-assn.org/doctorfinder/>**
 - The American Society of Hematology's (ASH) "Find a Hematologist" online at **<https://www.hematology.org/Patients/FAH.aspx>**

When you meet with the specialist, ask questions to get a better idea of the doctor's experience and to understand how the office works. See pages 43-44 for a full list of questions.

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. Is there a release form available so my family/caregiver can be given medical information?

Make sure you feel comfortable interacting with the doctor and the rest of the staff. You will be spending a lot of time speaking with the staff at the treatment center.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet ***Choosing a Blood Cancer Specialist or Treatment Center Facts*** at **www.LLS.org/booklets**, or you can contact our Information Specialists for a copy.

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 become actively involved in making decisions about your care.

When you meet with your doctor

- Ask questions. See pages 43-48 at the end of this Guide for a full list of questions. Visit www.LLS.org/WhatToAsk to find other “What to Ask” healthcare question guides.
 - What are my treatment choices?
 - Are there any clinical trials that I can join?
 - When do you think I should begin treatment?
 - How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later on. Ask the doctor and staff if recording is okay (cell phones have a “record” function; ask someone how to use it).
- Bring a caregiver, friend or family member who can listen to the doctor along with you, take notes and offer support.
- Make sure you understand what the doctor is saying. If you do not understand, ask the doctor to explain it again.

If you need more information or are not sure about your treatment choices, consider getting another opinion (a “second opinion”) from a different qualified doctor. If you are unsure or feel uncomfortable about how to tell your doctor you are getting a second opinion, call our Information Specialists to discuss a way that makes you comfortable. You may also want to check with your health insurance to ensure that a second opinion will be covered.

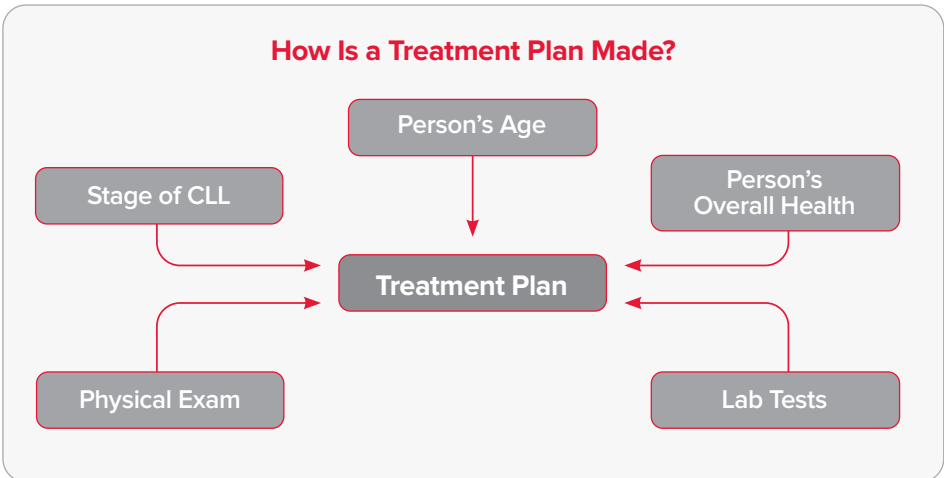
Treatment Planning

The goals of CLL treatment are to:

- Slow the growth of the CLL cells
- Provide long periods of remission (when there are no signs or symptoms of CLL)
- Improve survival
- Help people manage symptoms and complications of CLL such as infections, tiredness, fevers and night sweats

The treatment plan for a person with CLL depends on the:

- Stage of CLL (low-risk, intermediate-risk or high-risk) (see page 15)
- Physical exam and lab test results
- Person's overall health
- Person's age
- Genetic mutations in the CLL cells



CLL Staging. Many doctors use a system called **staging** to help predict the likely outcome of the disease and to plan treatment for people with CLL. There are three staging systems that doctors may use; these systems are called the **Rai staging system, the Binet staging system** and the **CLL International Prognostic Index (CLL-IPI)**. Although the Rai and Binet staging systems are still widely used, they have shown certain limitations in the ability to predict which patients will have a more aggressive disease and others who have less favorable responses to treatment. Genetic and molecular prognostic features of CLL have been integrated into the CLL-IPI. Talk to your doctor about what staging system they are using and how it can predict the responses to the therapy you receive.

WANT MORE INFORMATION?



You can view, print or order the free LLS book **Chronic Lymphocytic Leukemia at www.LLS.org/booklets** for more detailed information about staging systems. Or you can contact our Information Specialists for a copy.

Prognostic Factors. For CLL patients, there are several factors that may affect the likely outcome of their disease, called the **prognosis**. These factors may also help doctors determine the best treatment options.

Chromosome Changes. The doctor will use FISH and other tests to identify chromosome changes. Knowing that a patient has chromosome changes can also help the doctor figure out the best treatment option.

The following are some of the chromosome changes your doctor will be testing for:

- **Del(13q).** Some CLL patients are missing parts of chromosome 13 called “del(13q).” This is associated with a favorable outcome (if not associated with any other abnormality).
- **Del(17p).** Some CLL patients are missing parts of chromosome 17 called “del(17p)” which is linked to the mutation of the *TP53* gene. Patients with the del(17p)/*TP53* mutation do not respond well to either chemotherapy or chemoimmunotherapy, and have high-risk CLL (see page 22).
- **Del(11q).** Some CLL patients are missing parts of chromosome 11 called “del(11q).” This is associated with higher-risk disease.

Blood Lymphocyte Doubling Time. CLL patients whose lymphocyte count doubles in one year have higher-risk CLL. A lymphocyte number that remains stable generally indicates a lower-risk disease.

CD38. Some CLL cells have the protein marker CD38 on the surface of the cells. This marker is an indicator of high-risk CLL.

Beta2-Microglobulin (B₂M). B₂M is a protein that is shed from CLL cells. A higher level of B₂M in the blood may mean there are more CLL cells in the body.

CD49d. CD49d is a protein marker found on some CLL cells. CD49d is an indicator of higher-risk CLL.

IGHV Region Gene Mutation. In people with CLL, the genes in the *IGHV* region may or may not be mutated. The outlook is better for patients who have the *IGHV* region mutation. The outlook is worse for patients who do not have this mutation.

NOTCH1 Gene Mutation. CLL patients who have *NOTCH1* gene mutations may have higher-risk disease.

SF3B1 Gene Mutations. CLL patients who have *SF3B1* gene mutations may have a faster progression of disease and a less favorable outcome.

ZAP-70. ZAP-70 is a protein made on the surface of T cells. CLL patients that have increased ZAP-70 expression may be associated with higher-risk disease.

About CLL Treatments

WANT MORE INFORMATION?



You can view, print or order the free LLS book ***Chronic Lymphocytic Leukemia*** to learn more detailed information about CLL. Go to www.LLS.org/booklets, or contact our Information Specialists for a copy.

New treatments may have been approved since this book was printed. Check www.LLS.org/DrugUpdates or call **(800) 955-4572**.

Before you begin treatment, you and your doctor will discuss your treatment options. One option may be a clinical trial. Like all treatment options, clinical trials have risks and benefits. Be sure to think about all of your treatment options, including clinical trials.

Speak with your doctor about treatment sequencing. This means figuring out the best first treatment and the order of other treatments once you need therapy. Note that this may change as new treatments and drug combinations are approved.

Current therapies do not offer patients a cure for CLL, but there are treatments that have the potential to give patients longer remissions and a better quality of life. Treatments for CLL include:

- Watch and wait or active surveillance
- Targeted therapies
- Monoclonal antibody therapies
- Chemotherapy
- Chemo-immunotherapy
- Stem cell transplantation
- Supportive care
- Treatment in a clinical trial (see page 26)

A patient may receive different drugs from those described in this Guide. This may still be considered proper treatment. Speak to your doctor to find out what treatment is best for you.

Our Information Specialists can help you plan questions to ask your doctor about treatment.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

1. What is the stage of my CLL?
2. What are my treatment options, including clinical trials?
3. What is the goal of treatment?
4. What are the benefits and risks of these treatments?
5. Is there one treatment recommended over others?

Watch and Wait. Not all CLL patients need to start treatment immediately. Watch and wait is a valid treatment approach that means your doctor will watch your condition but not give you treatment unless you have signs or symptoms that appear or change. This approach includes:

- Regular medical examinations that include checking the size of your lymph nodes and spleen
- Regular blood testing to see whether the disease is stable or beginning to progress

You may think you should start treatment right away. But for people with low-risk (slow-growing) disease and no symptoms, it is often best not to start treatment immediately. With a watch-and-wait approach, you avoid the side effects of therapy until it is needed.

Between appointments, if you notice that you are having a number of infections, increased fatigue, night sweats, or you are generally not feeling well, contact your doctor. Do not wait for your next appointment to report these symptoms.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet titled ***Watch and Wait*** at www.LLS.org/booklets, or contact our Information Specialists for a copy.

When to Start Treatment. Some CLL patients can be managed with the watch-and-wait approach for years before their diseases progresses. The decision to begin treatment is based on a patient's symptoms, test results and the stage of CLL. Treatment will begin if your symptoms or test results show that the disease is growing.

Your doctor may advise you to begin treatment if you have one or more of the following factors:

- An increase in the number of CLL cells
- A decrease in the number of red blood cells
- A decrease in the number of platelets
- An increase in the size of the lymph nodes
- An increase in the size of the spleen and/or the liver
- The presence of CLL symptoms including
 - Fatigue
 - Night sweats
 - Unexplained weight loss
 - Fever without other evidence of infection

Beginning Treatment for CLL. Treatment of CLL is started when symptoms develop that are associated with active disease. Before beginning treatment, it is important for the patient to have the following tests:

- FISH, to determine if del(17p) or del(11q) is present
- DNA sequencing, to test for *IGHV* and *TP53* gene mutations
- Screening for hepatitis B exposure

Because CLL is typically a disease of elderly patients, the doctor will also evaluate a patient's fitness and identify other medical conditions or problems that may affect CLL treatment. CLL treatment options are determined by the patient's age, fitness and health.

After all these tests are done, CLL patients are most often placed into one of two categories based on mutation status. See pages 22-23 for treatment options based on these categories.

For a list of drugs used to treat CLL, see page 21. Information about side effects of treatment for CLL starts on page 27.

Targeted Therapies. These treatments are designed to attack (“target”) specific substances on cancer cells with less harm to normal, healthy cells. Most targeted therapies for CLL are given as pills and, in general, have milder side effects than chemotherapy. **Ibrutinib (Imbruvica®), idelalisib (Zydelig®), duvelisib (Copiktra®), acalabrutinib (Calquence®) and venetoclax (Venclexta®)** are all targeted therapies approved for CLL and are all given by mouth.

Monoclonal Antibody Therapies. These treatments use immune-system proteins (antibodies) that are made in the lab. Monoclonal antibody therapies aim for a specific target on the surface of the CLL cells. The antibody attaches to the cell and then the cell dies. In general, the side effects are milder than the side effects of chemotherapy.

Rituximab (Rituxan®), obinutuzumab (Gazyva®), alemtuzumab (Campath®), ofatumumab (Arzerra®), and rituximab plus hyaluronidase human (Rituxan Hycela®) are five FDA-approved monoclonal antibody therapies used to treat people with CLL. With the exception of Rituxan Hycela, which is given by injection subcutaneously (beneath the skin), the rest of these therapies are given intravenously (through an IV line).

Chemotherapy. This is a type of treatment designed to kill cancer cells. Some drugs are given by mouth (oral medication, like a pill). Other drugs are given through an IV line. Two or more drugs are often used together. The FDA-approved drugs **cladribine (Leustatin®)**, **fludarabine (Fludara®)** **pentostatin (Nipent®)**, **cyclophosphamide (Cytoxan®)**, **bendamustine hydrochloride (Bendeka®)** and **chlorambucil (Leukeran®)** are used to treat people with CLL.

Chemo-immunotherapy. This treatment combines chemotherapy drugs with the targeted therapy rituximab. Examples of these are:

- **FCR:** fludarabine, cyclophosphamide and rituximab
- **BR:** bendamustine and rituximab

Splenectomy. The spleen is an organ on the left side of the body, near the stomach. CLL cells can enlarge the spleen and cause discomfort in some people with CLL. Also, an enlarged spleen may lower the person's blood cell counts to dangerous levels. An operation to remove the spleen is called a **splenectomy**. Splenectomy is helpful for some people with CLL if the spleen is enlarged as a result of the disease. The operation may improve the person's blood cell counts.

Radiation Therapy. This treatment uses x-rays or other high-energy rays to kill cancer cells. Radiation therapy is sometimes used to treat a person with CLL who has an enlarged (swollen) lymph node, spleen or other organ that is blocking the function of a neighboring body part, such as the kidney or the throat. Radiation is rarely used for CLL.

Some Drugs Approved or in Clinical Trials for the Treatment of CLL

Targeted Therapy

- Acalabrutinib (Calquence®)
- Duvelisib (Copiktra®)
- Ibrutinib (Imbruvica®)
- Idelalisib (Zydelig®)
- Venetoclax (Venclexta®)

Monoclonal Antibodies

- Alemtuzumab (Campath®)
- Obinutuzumab (Gazyva®)
- Ofatumumab (Arzerra®)
- Rituximab (Rituxan®)
- Rituximab and hyaluronidase human (Rituxan Hycela®)*
*After the first dose of Rituxan, patients may be switched to Rituxan Hycela.

Chemotherapy

- Bendamustine hydrochloride (Bendeke®)
- Chlorambucil (Leukeran®)
- Cyclophosphamide (Cytosan®)
- Cladribine (2-CdA; Leustatin®)
- Fludarabine (Fludara®)
- Pentostatin (Nipent®)

New treatments may have been approved since this book was printed.
Check www.LLS.org/DrugUpdates or call **(800) 955-4572**.

Below are suggested first-line treatment regimens (the first treatment given to treat CLL):

Patients Without del(17p) or TP53 Mutations. The following are the first options for treatment for this group of patients. This group includes patients 65 years and younger without comorbidities (other health issues) and also those who are older than 65 years with comorbidities:

- Ibrutinib (Imbruvica®)
- Acalabrutinib (Calquence®), with or without obinutuzumab (Gazyva®)
- Venetoclax (Venclexta®) in combination with obinutuzumab

Other treatment options for these patients include:

- Ibrutinib in combination with obinutuzumab
- FCR—Fludarabine (Fludara®), cyclophosphamide (Cytoxan®) and rituximab (Rituxan®)
- FR—Fludarabine (Fludara®) and rituximab (Rituxan®)

Patients With del(17p) or TP53 Mutations. Patients with del(17p) or TP53 mutations, whether young or older, either do not respond well to treatment or are likely to have early relapses if the first treatment is any type of chemo-immunotherapy. The following treatments are for patients with del(17p) and should be used as a first option:

- Ibrutinib (Imbruvica®)
- Acalabrutinib (Calquence®), with or without obinutuzumab (Gazyva®)
- Venetoclax (Venclexta®) in combination with obinutuzumab
- Less effective regimens include rituximab (Rituxan®) plus high-dose methylprednisolone or alemtuzumab (Campath®)

If these treatments are not appropriate or effective, a clinical trial should be considered (see page 26). Allogeneic stem cell transplantation may also be an option (see page 23).

Relapsed or Refractory CLL

Some CLL patients **relapse**. A relapse is the return of cancer after it has been in remission for more than six months. Other patients have **refractory** CLL. Refractory CLL is cancer that is not in remission at the end of treatment. Cancer is also considered refractory if it is getting worse within 6 months after treatment has ended.

There are many treatment options for people with CLL. People who are treated for relapsed or refractory CLL often have good quality years of remission after more treatment.

It is important to have another FISH test before additional treatments because the results of the FISH test can help your doctor determine the next therapy. New mutations can develop over time or as a result of past treatments.

The following drugs and treatments can be used to treat relapsed or refractory CLL:

- **Ibrutinib (Imbruvica®)**
- **Venetoclax (Venclexta®)**, alone or with **rituximab (Rituxan®)**
- **Acalabrutinib (Calquence®)**
- **Duvelisib (Copiktra®)**
- **Idelalisib (Zydelig®)** in combination with rituximab
- **Ofatumumab (Arzerra®)**
- Combinations of **ibrutinib** or **venetoclax** with anti-CD20 antibodies
- **Alemtuzumab (Campath®)**, alone or in combination with other treatments
- Allogeneic stem cell transplantation (see below)
- CAR T-cell therapy (see page 24)

Allogeneic Stem Cell Transplantation. Allogeneic stem cell transplantation is a treatment option for people who have relapsed or refractory high-risk CLL.

An allogeneic transplant is a treatment that uses stem cells from a donor. The stem cells in the donor's blood must be a "match" to the patient. The donor may be a brother or sister (siblings are most often the best match). The donor may also be an unrelated person with stem cells that match the patient's. Stem cells may also come from cord blood (the blood in the umbilical cord after a baby's birth).

For patients who may not be able to withstand the high doses of chemotherapy that are given to patients during stem cell transplant, there is another type of allogeneic stem cell transplant. **Reduced-intensity allogeneic stem cell transplant** (also called a **nonmyeloablative transplant**) is less harsh and uses lower doses of chemotherapy than a standard allogeneic transplant. Some older or sicker patients may be helped by this treatment.

An allogeneic stem cell transplantation has a high risk of serious complications. Your doctor will explain the benefits and the risks if transplantation is suggested for you.

CAR T-Cell Therapy. This is a type of immunotherapy that uses a person's own immune cells (T cells) to kill cancer cells. T cells are taken from a patient's blood and sent to a laboratory. There, the T cells are genetically modified to allow them to identify and attack cancer cells. The T cells are then re-infused into the patient's blood.

Clinical trials are in progress to study the use of CAR T-cell therapy in the treatment of chemotherapy-resistant CLL, relapsed CLL, or CLL that has not responded to ibrutinib.

Please call **(800) 955-4572** or visit the Clinical Trial Support Center at **www.LLS.org/CTSC** for more information about clinical trials.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet titled ***Chimeric Antigen Receptor (CAR) T-Cell Therapy Facts*** at **www.LLS.org/booklets**, or contact our Information Specialists for a copy.

Financial Challenges for CLL Patients

There have been significant advances in CLL therapy. New treatments, such as acalabrutinib (Calquence®), ibrutinib (Imbruvica®), idelalisib (Zydelig®), venetoclax (Venclexta®) and duvelisib (Copiktra®), have improved survival and quality of life for CLL patients. The prices of these medications, however, are significantly higher than previous standard treatments. Ibrutinib, idelalisib and duvelisib require continuous daily use until the treatment no longer works or the disease progresses. Venetoclax therapy can be completed in a set amount of time: 1 year for first-line treatment and 2 years for relapsed or refractory treatment.

Speak to your doctor if you have concerns about being able to afford your CLL medication. A member of your treatment team may be able to provide information and resources that can help. Health insurance plans may not cover all the costs of cancer care, but there are resources you can find to assist in paying for prescription drugs.

In addition, several major drug manufacturers currently provide patient assistance or prescription assistance programs. These companies may be able to help by providing both insured and uninsured patients with free or reduced-cost medications.

For more assistance, call our LLS Information Specialists at **(800) 955-4572** for information about patient prescription assistance programs, co-pay programs and LLS financial assistance programs.

WANT MORE INFORMATION?



You can view, print or order the free LLS book ***Cancer and Your Finances*** at www.LLS.org/booklets, or contact our Information Specialists for a copy.

About Clinical Trials

There are new treatments under study for patients with CLL. New treatments are studied in clinical trials. Clinical trials are also used to study new uses for approved drugs or treatments, such as changing the dose of a drug or giving a drug along with another type of treatment. Some clinical trials combine drugs for CLL in new sequences or dosages.

There are clinical trials for

- Patients newly diagnosed with CLL
- Patients who did not get a good response to treatment (refractory disease)
- Patients who relapsed after treatment

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

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

1. Is a clinical trial a treatment option?
2. How can I find out if insurance covers the cost of the clinical-trial treatment and treatment-related costs, such as testing?
3. Who pays for the travel costs to get to the clinical trial?

Ask your doctor if treatment in a clinical trial may be right for you. For more information, please call **(800) 955-4572** to speak with an LLS Information Specialist who can provide more information about clinical trials and help search for a clinical trial for you. Personalized clinical-trial navigation by trained nurses is also available through the Clinical Trial Support Center. Visit **www.LLS.org/CTSC** for more information.

PART 4 Side Effects, Treatment Response and Follow-Up Care

Overview of This Section

- Treatment side effects vary depending on the type of treatment. For example, the side effects of targeted therapies are different from the side effects of chemotherapy.
- Some of the common side effects of CLL treatment may include tiredness, fever, rash, nausea, diarrhea and pain.
- People with CLL should see their primary care doctor and a cancer specialist regularly for follow-up care.

Side Effects of CLL Treatment

The term **side effect** is used to describe a problem that occurs when cancer treatment affects healthy tissues or organs and causes symptoms that are uncomfortable or even harmful for the patient.

Treatment side effects vary depending on the type of treatment. For example, the side effects of targeted therapies are different from the side effects of chemotherapy. Patients react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be uncomfortable and difficult. Some side effects are serious and last a long time. Usually side effects go away once treatment ends. You should talk with your doctors about potential side effects before you begin any type of treatment.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for full list of questions.

1. What are the common side effects of this treatment?
2. What side effects should be reported to the healthcare team right away?
3. How can potential side effects be prevented or managed?
4. How long will the side effects last?

Blood Cell Counts. CLL and its treatment may affect your blood cell counts:

- The number of red blood cells may decrease to lower-than-normal (anemia). Red blood cell transfusions (red blood cells that are donated and given to the patient) may be needed in order to increase red blood cell counts.

- Patients may also have a drop in the number of platelets in their blood (thrombocytopenia). A platelet transfusion may be needed to prevent bleeding if a patient's platelet count is very low.
- A big drop in the number of white blood cells (neutropenia) may lead to an infection. Infections are usually treated with antibiotics. People with repeat infections may also get injections (shots) of immunoglobulin (gamma globulin) on a regular basis to help prevent new infections.

For some patients who experience long periods of low white blood cell counts, doctors may prescribe a type of drug called a growth factor that helps the bone marrow make more white blood cells. Examples of white blood cell growth factors are filgrastim (Neupogen®), pegfilgrastim (Neulasta®) and sargramostim (Leukine®).

Vaccinations. Due to the high risk of infections in CLL patients, vaccination for pneumococcal pneumonia should be repeated every 5 years, and a yearly flu vaccination is recommended. CLL patients should never receive live vaccines. For example, patients should not receive Zostavax®, a live shingles vaccine, but can receive the inactivated shingles vaccine called Shingrix®. COVID-19 vaccines are also recommended, but they have not been tested in patients with CLL as of this printing. Talk to your doctor for more information.

Other Treatment Side Effects. Some possible side effects of CLL treatment include:

- Rash
- Heartburn
- Infections
- Achy feeling
- Diarrhea
- Constipation
- Extreme tiredness
- Hair loss
- Low blood pressure
- Mouth sores
- Upset stomach and vomiting

Talk to your doctor about the possible side effects and long-term effects of your treatment. You can also call our Information Specialists.

WANT MORE INFORMATION?



You can view, print or order free LLS information about managing side effects (filter by Side Effect Management) and long-term effects at www.LLS.org/booklets, or contact our Information Specialists for copies.

Treatment Response

Treatment Outcomes. People with CLL have a range of responses after treatment. Talk to your doctor about your test results and your goals for treatment. Your doctor may use the following terms to talk about responses to treatment.

- **Complete Remission (Complete Response).** This is the best outcome. Enlarged lymph nodes and organs are back to normal size. Blood counts are within normal range, and there are no CLL symptoms, such as fever and night sweats.
- **Partial Remission (Partial Response).** There is at least a 50 percent reduction in the size of enlarged lymph nodes and organs. Blood counts are returning to normal (there is also at least a 50 percent reduction in the number of blood lymphocytes).
- **Stable Disease.** Stable disease is less improvement than partial remission, but the cancer is not getting worse.
- **Progressive Disease.** Progressive disease is cancer that is growing or getting worse.

Minimal/Measurable Residual Disease. Some CLL patients may achieve a complete remission after first-line treatment but still may have a small number of leukemia cells in the body. These remaining leukemia cells are called **minimal/measurable residual disease (MRD)**. These leukemia cells can become active and start to multiply, causing a relapse of the disease.

Very sensitive tests may be performed to detect the presence of this small number of leukemia cells. The tests to detect MRD in people with CLL are called flow cytometry and polymerase chain reaction (PCR). These tests may help the doctor identify which patients may need more treatment.

WANT MORE INFORMATION?



You can view, print or order the free LLS booklet ***Minimal Residual Disease (MRD)*** at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Follow-Up Care

CLL patients should see their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. At these visits, the doctor will check your health, blood cell counts and, if needed, perform or order other tests to evaluate your treatment progress as well as to see if there are any signs of relapse. You should also tell the doctor of any changes that you notice (for example, infections, enlarged lymph nodes, night sweats, etc).

You should talk with the doctor about how often to have follow-up visits. You can ask your doctor what tests will be needed and find out how often you need to have these tests. It is important to keep a record of your cancer treatments, including the drugs and procedures you received and the time period you received them, so that your doctor can follow up on specific long-term effects that may be associated with your treatment. See page 42 for a place to list treatments.

Here are some questions you may want to ask your healthcare team. See pages 43-48 for a full list of questions.

1. Who should I work with to ensure life-long follow up?
2. Will I continue to see this healthcare team?
3. What information can be provided to my primary doctor about past treatment and what may be needed in the future?

To find a survivorship clinic (a place that helps cancer patients live well after cancer treatment) and other resources for CLL survivors, contact our Information Specialists.

Take Care of Yourself

- Keep all appointments with the doctor.
- Talk about how you feel with the doctor at each visit.
- Ask any questions you may have about side effects.
- People with CLL may have more infections than other people. Follow your doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat 4 or 5 smaller meals instead of 3 big ones.
- Keep a record of your cancer diagnosis, treatment, and follow-up care needs. This is often called a "survivorship care plan." Ask your doctor for a written survivorship care plan. Share this information with any new healthcare providers you see. The plan should include the following information:
 - List of all healthcare providers
 - Diagnosis summary with specifics such as subtype and/or genetic markers
 - Treatment summary with specifics such as the names, dates, and dosages of chemotherapy or other drugs, site of radiation treatment, surgery and/or transplantation information, response to treatment, and side effects
 - Maintenance treatment information, if applicable
 - List of possible late effects
 - Schedule for ongoing monitoring with recommended tests, frequency and coordinating provider
 - Health and wellness recommendations such as nutrition, exercise or other disease screenings
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. Patients 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. 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 know about CLL 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 can and should be treated even when a person is being treated for CLL. Treatment for depression has benefits for people living with cancer.

RESOURCES AND INFORMATION

LLS offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

For Help and Information

Consult with an Information Specialist. Information Specialists are highly trained oncology social workers, nurses and health educators. They offer up-to-date information about disease, treatment and support. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email and Live chat: www.LLS.org/InformationSpecialists

Clinical Trials (Research Studies). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

Free Information Booklets. LLS offers free education and support booklets that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit www.LLS.org/programs for more information.

Financial Assistance. LLS offers financial support, including insurance premium and medication co-pay assistance, to eligible individuals with blood cancer. For more information, please:

- Call: (877) 557-2672
- Visit: www.LLS.org/Finances

One-on-One Nutrition Consultations. Access free one-on-one nutrition consultations provided by a registered dietitian with experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit www.LLS.org/nutrition for more information.

LLS Health Manager™ App. This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Please visit www.LLS.org/HealthManager to download for free.

LLS Coloring for Kids™. This free coloring app allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. The app includes blank canvases, general coloring pages and pages from LLS coloring books. This app can be used anywhere and may help pass time in waiting rooms or during treatment. Visit www.LLS.org/ColoringApp to learn more and download.

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit www.LLS.org/SuggestedReading to find out more.

Community Resources and Networking

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients reach out and share information. Please visit www.LLS.org/chat for more information.

LLS Chapters. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection® Program* (a peer-to-peer support program), local support groups and other great resources. For more information about these programs or to contact your chapter, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/ChapterFind

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to obtain the directory.

Advocacy. The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

Information for Veterans. Veterans 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, please

- Call: the VA (800) 749-8387
- Visit: www.publichealth.va.gov/exposures/AgentOrange

World Trade Center Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov and enter “depression” in the search box

Health Terms

Antibiotic. A drug that is used to treat infections caused by bacteria and fungi.

Antibody. A protein made by blood cells when they are invaded by bacteria, viruses or other harmful foreign substances called “antigens.” Antibodies help the body fight invaders that cause illness. Antibodies can also be made in the lab and are used to help detect and treat certain types of cancer.

Baseline testing. Test results are taken before treatment and these become the baseline. Test results taken after treatment are compared to the baseline to see improvement (or not). For example, in patients with CLL, the number of lymphocytes in the blood will be measured before treatment begins (baseline) and then afterwards to see if the treatment has had an effect on the number of lymphocytes in the blood.

Beta₂-microglobulin (B₂M). A protein normally found on the surface of many cells, including lymphocytes, and in small amounts in the blood and urine. A high level of B₂M in the blood or urine may be a sign of high-risk CLL.

Bone marrow. The spongy material in the center of the bones where blood cells are made.

Bone marrow aspiration. A procedure to remove and examine bone marrow cells to see if they are normal. A liquid sample containing cells is taken from the marrow and then the cells are looked at under a microscope.

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 bone marrow cells is taken from the body, and the cells are looked at under a microscope.

Chemotherapy. Treatment that stops the growth of cancer cells, either by killing the cancer cells or by stopping them from dividing.

Chromosomes. Thread-like structures within cells that carry genes. Human cells have 23 pairs of chromosomes. The number and/or shape of chromosomes may not be normal in cancer cells.

Clinical trial. A careful study done by doctors to test new drugs or treatments, or to test new uses for already approved drugs or treatments. The goals of clinical trials for blood cancers are to improve treatment and quality of life and to find cures.

Diagnose. To identify a disease. Doctors diagnose diseases, using a person's signs and symptoms, as well as many tests.

FDA. The 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.

Flow cytometry. Flow cytometry is a laboratory method that evaluates individual cells by checking for the presence or the absence of certain protein markers on the cell surface.

Fluorescence in situ hybridization (FISH). A test for studying abnormal genes and chromosomes in cells and tissues. The results of this test can be used to plan treatment and to measure the results of treatment.

Hematologist-oncologist. A doctor who specializes in treating cancer in the blood.

Immune system. A network of cells, tissues and organs in the body that defend the body against infection.

Immunoglobulin. A protein made by B cells and plasma cells that helps the body fight infection.

Immunotherapy. A type of treatment that uses substances to stimulate or suppress the immune system to help the body fight cancer and other diseases.

Intravenous (IV) injection. An injection into a vein, IV usually refers to the method of giving a drug through a needle or tube inserted into a patient's vein.

Lymph node. A small bean-shaped organ that is part of the body's immune system. Lymph nodes contain lymphocytes (white blood cells) that help the body fight infection and disease.

Lymph vessel. A thin tube that carries lymphatic fluid and white blood cells through the lymphatic system.

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

Marrow. See Bone marrow.

Monoclonal antibody therapy. A treatment that targets and kills certain cancer cells. In general, it does not cause as many side effects as chemotherapy.

Oncologist. A doctor who specializes in treating patients who have cancer. See hematologist-oncologist.

Polymerase chain reaction (PCR). A lab test that can measure the presence of cancer cell markers in the blood or bone marrow. PCR is used to detect cancer cells that may remain after treatment but that cannot be detected by other tests.

Plasma. The clear, liquid part of the blood that carries blood cells.

Platelet. A type of blood cell that helps prevent or stop bleeding. Platelets help form blood clots to slow or stop bleeding and to help heal wounds.

Red blood cell. A type of blood cell that carries oxygen to all parts of the body. In healthy people, red blood cells make up almost half of the cells in the blood.

Refractory CLL. CLL that has not responded to initial treatment.

Relapsed CLL. CLL that comes back after it has been successfully treated.

Remission. No signs or symptoms of a disease after treatment.

Spleen. An organ that is part of the lymphatic system. The spleen is located on the left side of the body near the stomach. It contains white blood cells that fight infections.

Stem cell. A type of cell found in the bone marrow that eventually matures into different types of cells: red blood cells, white blood cells, and platelets.

White blood cell. A type of cell in blood that helps the body fight infection.

MY HEALTHCARE TEAM CONTACT LIST

Use this list to remember names and contact information for members of your healthcare team.

CAREGIVER NAME:

Address: _____

Phone Number/Fax number: _____

Email address: _____

Additional information: _____

PRIMARY CARE DOCTOR NAME:

Address: _____

Phone Number/Fax number: _____

Email address: _____

Additional information: _____

PHARMACY NAME:

Address: _____

Phone number/Fax number: _____

Additional information: _____

Information Specialists:

Phone: (800) 955-4572

Email and live chat: www.LLS.org/InformationSpecialists

HEMATOLOGIST-ONCOLOGIST NAME:

Address: _____

Phone number/Fax number: _____

Email address: _____

Website/Portal: _____

Additional information: _____

NURSE/NURSE PRACTITIONER NAME:

Phone number/Fax number: _____

Email address: _____

Additional information: _____

SOCIAL WORKER NAME:

Address: _____

Phone number/Fax number: _____

Email address: _____

Additional information: _____

INSURANCE CASE MANAGER/
CARE COORDINATOR NAME:

Address: _____

Phone number/Fax number: _____

Website or email address: _____

Additional information: _____

PHYSICIAN ASSISTANT NAME:

Address: _____

Phone number/Fax number: _____

Email Address: _____

Additional information: _____

NURSE NAVIGATOR NAME:

Address: _____

Phone number/Fax number: _____

Email address: _____

Additional information: _____

OTHER:

Address: _____

Phone number/Fax number: _____

Email address: _____

Additional information: _____

OTHER:

Address: _____

Phone number/Fax number: _____

Email address: _____

Additional information: _____

MY LIST OF TREATMENTS

Use this space to list your treatments and when you took them.

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

DATE: _____

Treatment: _____

QUESTION GUIDE: MY FIRST DOCTOR'S VISIT

Asking questions will help you take an active role in managing your (or your loved one's) care. If you do not understand any part of the information your healthcare provider gives you, ask them to explain it in another way. The following are questions you may want to ask your healthcare team.

When you meet with the doctor, nurse and healthcare team, ask a few questions to get a better idea of the doctor's experience and to understand how the office works.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which patients may not be old enough or able to make their own decisions. A parent, relative, or caregiver may be assisting or making the decisions.)

Questions for the Doctor

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it normally take to receive a return phone call?
4. How can you be contacted when there are questions?
5. How can you be contacted at night? On weekends? On holidays?
6. Who are the other members of the team that I should be aware of?
7. Is there a release form available so my family/caregiver can be given medical information?

Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

1. How long would I (we) have to wait for appointments?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it usually take to receive a return phone call?
4. Will there be nurses, social workers and case managers available to help with support needs and quality-of-life concerns?
5. Does your office accept my (our) insurance? Is it considered in-network?

To print copies of other question guides, go to www.LLS.org/WhatToAsk or call **(800) 955-4572**.

Question Guide: Treatment and Follow-Up Care

Talk with the doctor and ask questions about how they plan to treat your (your loved one's) leukemia. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which patients may not be old enough or able to make their own decisions. A parent, relative, or caregiver may be assisting or making the decision.)

DOCTOR'S NAME: _____

Date of appointment or phone call: _____

Write down your diagnosis:

Write down your stage of CLL:

Before Treatment Begins

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make decisions?
5. What is the stage?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is there one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

Testing

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results back?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

Treatment

1. Will this be an in-hospital or an outpatient treatment?
If the treatment is outpatient:
 - 1a. Is it alright to attend work or school during treatment?
 - 1b. Will someone be needed to drive me home after treatment?
2. What kind of testing will be done to monitor this disease and treatment? How often will testing be needed? Where is the testing done?
3. How will we know if the treatment is effective? What options are available if the treatment is not effective?
4. What is the likely outcome of the disease (prognosis)?

Side Effects

1. What are the common side effects for this treatment?
2. What side effects should be reported to the healthcare team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?
5. How should I report side effects (phone call, at the office visit, etc)?

Social/Financial Concerns

1. Are there any side effects that will affect appearance or ability to do a job/go to school?
2. What kind of financial and social support services are available to me and my family?
3. How can I (we) find out if insurance will cover the costs of the treatment or the study (clinical trial) treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I (we) do not have insurance coverage, how can the healthcare team help get the treatment needed? Is there someone I can speak to for assistance?
6. If I (we) get in a study treatment (clinical trial), will I (we) be responsible for paying treatment-related costs, such as tests, travel or for clinical-trial drugs?
7. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs such as testing?

Follow-Up Care and Long-Term and Late Effects

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) continue to see this healthcare team?
3. How can I (we) be monitored for long-term and late effects of treatment?
4. What types of long-term and late effects should be brought to the healthcare team's attention?
5. If I (we) have side effects later, how can the healthcare team be reached?
6. What information can be provided to a primary doctor about this treatment?

To print copies of other question guides, go to www.LLS.org/WhatToAsk or call **(800) 955-4572**.



Get support. Reach out to our **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society team consists of highly trained oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individualized clinical-trial searches

Contact us at
800-955-4572 or
**www.LLS.org/
InformationSpecialists**

(Language interpreters can be requested)





For more information, please
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800.955.4572 (Language interpreters
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**BEATING
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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.