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PATIENTS & CAREGIVERS

# The CML Guide: Information for Patients and Caregivers



Revised **2023**

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

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**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, and optimism. Finding 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](http://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

# Inside This Guide

## 2 Introduction

## 3 Part 1 Chronic Myeloid Leukemia

Overview

About Bone Marrow, Blood and Blood Cells

About CML

Signs and Symptoms

Diagnosis

Tracking Your CML Tests

Phases of CML

## 12 Part 2 Treating CML

Overview

Finding the Right Doctor

Ask Your Doctor

Before-Treatment Considerations

About CML Treatments

Treating CML by Phase

Gene Mutation Testing

Financial Concerns

Children and Young Adults With CML

Pregnancy, Fertility and TKIs

## 28 Part 3 Clinical Trials

About Clinical Trials

## 29 Part 4 Treatment Response and Follow-Up Care

Overview

Measuring Treatment Response

Treatment-Free Remission

Follow-Up Care

Take Care of Yourself

## 33 Resources and Information

## 37 Health Terms

## 40 My Healthcare Team Contact List

## 43 My List of Treatments

### Question Guides

## 44 My First Doctor's Visit

## 46 Treatment and Follow-Up Care

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## INTRODUCTION

Chronic myeloid leukemia (CML) is a type of blood cancer that starts in the bone marrow and invades the blood. It is also known as chronic myelogenous leukemia, chronic granulocytic leukemia and chronic myelocytic leukemia.

The number of people who have CML and who are living well is increasing.

- About 8,860 people in the United States were expected to be diagnosed with CML in 2022.
- About 58,736 people in the United States were living with or are in remission from CML as of 2018.

Many new CML drugs have been approved since 2001. For most patients, these drugs have changed CML from a life-threatening disease to a chronic condition that can be managed with lifelong oral therapy (treatments given by mouth such as pills and capsules).

Other new treatments are being studied in clinical trials. Progress toward a cure is under way.

**Visit [www.LLS.org/booklets](http://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 more detailed, free LLS booklet *Chronic Myeloid Leukemia* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

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

**Feedback.** Visit [www.LLS.org/PublicationFeedback](http://www.LLS.org/PublicationFeedback) to make suggestions about this booklet.

## PART 1 Chronic Myeloid Leukemia

### Overview

- 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.
- Chronic myeloid leukemia (CML) starts with a change (mutation) to a single stem cell in the bone marrow.
- CML is diagnosed with blood and bone marrow 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 bone where blood cells are made.

**Blood cells** begin as stem cells in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets. After the cells 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 feel tired or short of breath. It may 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.

- Lymphocytes are infection-fighting cells called:
  - B cells
  - T cells
  - NK cells

○ Germ-eating cells are called:

○ Neutrophils

○ Monocytes

**Platelets** help stop bleeding by clumping together (called **clotting**) at the site of an injury.

**Plasma** is the liquid part of the blood. 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 listed below are for adults. They may be a little different from lab to lab and for children and teens.

### Red blood cell (RBC) count

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

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

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

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

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

### Platelet count

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

### White blood cell (WBC) count

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

### Differential (also called diff)

- Shows the part of the blood made up of different types of white cells
- Counts the types of white cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils)
  - Normal adult white blood cell count: 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils

# About CML

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

CML is a type of cancer that begins in the bone marrow. A person can get CML at any age, but most people who have CML are adults. Only a small number of children are diagnosed with CML.

CML starts with a change to a single stem cell in the bone marrow. This means:

- A normal stem cell mutates (changes)
- Mutated cells multiply into many cells (CML cells)

Without treatment, the following changes take place:

- The number of red blood cells becomes lower than normal
- The number of white blood cells becomes higher than normal and continues to grow

**Chromosomes and Genes.** Normal cells have 23 pairs of chromosomes that are numbered from 1 to 22 plus one pair of sex chromosomes (the 23rd chromosome is called XX for females and XY for males). Chromosomes are structures in the cells that contain genes. The genes give instructions to the cells.

**The Philadelphia Chromosome.** In CML cells, a change takes place on chromosome 22. The changed chromosome 22 is known as the **Philadelphia chromosome**. It is also called the **Ph chromosome**. The Ph chromosome is created when a piece of chromosome 22 breaks off and attaches to the end of chromosome 9. A piece of chromosome 9 also breaks off and attaches to the end of chromosome 22.

**The *BCR::ABL1* Cancer Gene.** The break on chromosome 22 involves a gene called ***BCR***. The break on chromosome 9 involves a gene called ***ABL1***. The *BCR* and *ABL1* genes combine to make the CML-causing gene (oncogene) called ***BCR::ABL1***. This gene makes an abnormal protein that signals the body to make too many granulocytes (white blood cells). The white blood cells that have the *BCR::ABL1* oncogene are called “leukemia cells” or “CML cells.” Leukemia cells are abnormal. They do not become healthy white blood cells, and they do not die when they should. Over time, the leukemia cells build up in the bone marrow and crowd out healthy blood cells.

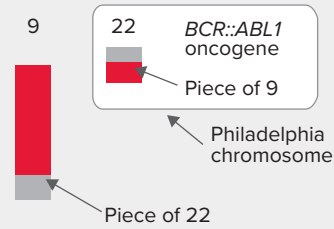


## How the *BCR::ABL1* Cancer-Causing Gene (Oncogene) Is Created

### Normal Chromosomes



### CML Chromosomes



- A piece of the *ABL1* gene on chromosome 9 breaks off.
- A piece of the *BCR* gene on chromosome 22 breaks off.
- These 2 pieces switch places; this is called **translocation**.
- The switch leads to the cancer gene called ***BCR::ABL1***.

**Causes of CML.** Doctors do not know why the *BCR::ABL1* gene that leads to CML forms in some people but not in others.

People treated with high-dose radiation therapy for other cancers have a small increase in risk of CML. But most people treated for cancer with radiation do not develop CML. And most people with CML were not exposed to high-dose radiation. There is no link between dental or medical x-rays and increased risk of CML. You cannot catch CML from someone else.

## Signs and Symptoms

Healthy people often have a sign or a symptom when they get an illness or a disease.

A **sign** is a change in the body that the doctors sees in an exam or test result. A **symptom** is a change in the body that the patient can see or feel.

CML signs and symptoms tend to develop slowly. Many of the signs and symptoms of CML are also signs and symptoms of other illnesses. Most people with these signs and symptoms do not have CML.

People with symptoms of CML often have:

- Weakness
- Tiredness
- Shortness of breath during everyday activities
- Fever
- Bone pain
- Unexplained weight loss
- Pain or a feeling of fullness below the ribs on the left side due to an enlarged spleen
- Night sweats

## Diagnosis

Many people with CML do not have symptoms when they are diagnosed with it. CML is often found during blood tests for an unrelated illness or during a routine checkup. CML is diagnosed with blood tests and bone marrow tests.

**Here are some questions you may want to ask your healthcare team.**

See pages 44-49 for a full list of questions.

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

**Blood Tests.** Testing for CML includes blood cell counts and a blood cell examination.

- Blood cell counts. The doctor orders a lab test called a **complete blood count (CBC)** to check the numbers of different kinds of blood cells. With CML, the number of white blood cells is typically higher than normal and may be very high. The red blood cell count may be lower than normal. The number of platelets may be higher or lower than normal.

- Blood cell examination. The cells are stained (dyed) and looked at with an instrument called a **light microscope**. A person with CML has a small number of developing cells called **blast cells** in the blood. Blast cells are immature undeveloped blood cells that are not found in the blood of healthy individuals.

**Bone Marrow Tests.** Some signs of CML do not show up in blood tests. The doctor has to look at a small number of cells (a sample) from the bone marrow. The samples of cells are obtained by procedures known as **bone marrow aspiration** and **bone marrow biopsy**.

### 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**—A sample of fluid with cells is removed from the bone marrow.

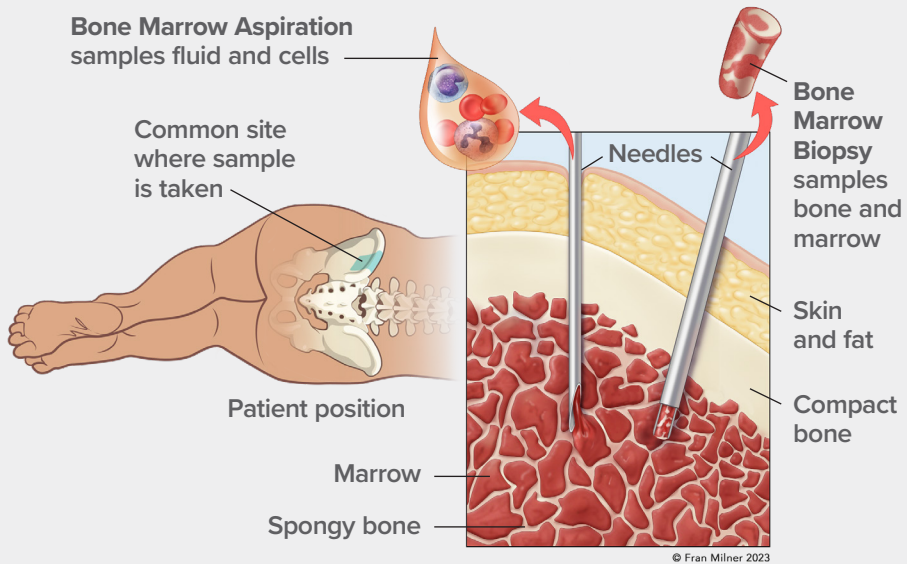
**Bone Marrow Biopsy**—A very small amount of bone filled with marrow cells is taken from the body.

Both bone marrow tests are done with special needles. Some patients are awake for the procedure. The patient gets medication first to numb the part of the body from which samples will be taken of fluid and/or cells. Some patients are given a drug that makes them sleep during the procedure. The samples of fluid or cells are usually taken from the patient’s hip bone.

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

**Visit [www.LLS.org/3D](http://www.LLS.org/3D) to view an interactive 3D image that will help you visualize and better understand the bone marrow aspiration and biopsy procedures.**

## 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:** One needle goes into bone marrow to get a liquid sample for aspiration (left) and the other needle goes inside the bone for a bone biopsy (right). The needle for aspiration is thinner than the one for biopsy.

**Cytogenetic Testing.** Samples of the bone marrow cells are examined under a microscope to study the chromosomes. This is called a **cytogenetic analysis**. The examiner looks at a “map” of the chromosomes in the cell. The map is called a **karyotype**. The Philadelphia (Ph) chromosome in a CML cell can be detected on the karyotype. The presence of the Ph chromosome is important information that—along with information about high white blood cell counts—helps the doctor diagnose CML.

**FISH.** A special test called **fluorescence in situ hybridization** or FISH can detect CML cells that may not show up on a standard cytogenetic test for the Ph chromosome.

**Quantitative Polymerase Chain Reaction (qPCR).** A qPCR test can detect a very small number of CML cells. A qPCR test can be done on cells taken from the blood or bone marrow. The qPCR test may also be used to monitor how well treatment is working. A qPCR test is recommended every 3 months at first. Even for patients with relatively deep disease remissions lasting at least 2 years, the test should be done every 3 to 6 months.

## Tracking Your CML 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 the reports by date.
- Find out if and when follow-up tests are needed.
- Mark appointments that are coming up on your calendar.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Understanding Lab and Imaging Tests* and *Understanding Genetics*. Go to [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

## Phases of CML

Once doctors diagnose cancer, they need to know how much cancer is in the body and where it is located. For most types of cancer, doctors assign a stage based on the size of a cancerous growth (called a **tumor**) and then determine whether the cancer has spread to other parts of the body. However, CML does not manifest as a tumor and is not staged in the same way as most cancers. Instead, CML is categorized into three groups called “phases.” Knowing your phase of CML helps doctors determine your prognosis (how serious your cancer is and your chances of survival) and plan the best treatment for you.

**Chronic Phase CML.** Most people have chronic phase CML when they are diagnosed. CML symptoms are milder in the chronic phase. White blood cells can still fight infection. Once people with chronic phase CML start treatment, they can usually go back to their day-to-day activities. If CML is not treated, it will progress to the next, more serious, accelerated phase.

**Accelerated Phase CML.** People with accelerated phase CML may develop anemia (a decreased number of red cells in the blood). The number of white blood cells and the number of blast cells in the blood both increase.

The number of platelets may increase or decrease and the spleen may swell. People with accelerated phase CML may feel ill. If CML is not treated, it will progress to the next, more serious, blast phase.

**Blast Crisis Phase CML.** People with blast crisis phase CML have an increased number of blast cells in their bone marrow and blood. The numbers of red blood cells and platelets drop. People may have infections or bleeding. They may be tired or have shortness of breath, stomach pain or bone pain. Blast phase behaves like an acute form of leukemia.

## PART 2 Treating CML

### Overview

- People with CML should choose a doctor who is a specialist in both diseases of the blood and cancer. This type of doctor is called a **hematologist-oncologist**.
- 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 Guides* on pages 46-49.
- If you want children in the future, or if you are the parent of a child with CML, ask about fertility (the ability to have a child). Find out what treatments may cause problems with fertility and what choices you have.
- For most people with CML, treatment begins with targeted drugs called **tyrosine kinase inhibitors (TKIs)**. These drugs are taken orally (by mouth).
- It is important to take TKIs as prescribed by your doctor. Not taking the correct dose can affect how well the treatment works.

### Finding the Right Doctor

Choose a doctor who specializes in treating CML 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. An oncologist is a doctor who has special training in cancer. A hematologist-oncologist has special training in both diagnosing and treating blood cancers.

If your local medical center does not have a hematologist-oncologist, ask the cancer specialist you see if they can consult with a leukemia specialist at another medical center. Always check to see if your health insurance covers the services of the doctors (and the hospital associated with them), or the hospital you choose for your treatment.

### **How to Find a Hematologist-Oncologist**

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center.
- 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, doctor, nurse or other healthcare team members, ask questions to get a better idea of the doctor’s experience and to understand how the office works. Some sample questions are below. See pages 44-45 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 this staff and others at this treatment center.

#### **WANT MORE INFORMATION?**



You can view, print or order the free LLS fact sheet *Choosing a Blood Cancer Specialist or Treatment Center Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or you can contact our Information Specialists at (800) 955-4572 for a copy.

## Ask Your Doctor

Talk with the doctor and ask questions about how they plan 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. Below are a few questions to ask as well as some suggestions when asking questions. See pages 46-49 at the end of this Guide for a full list of questions. Visit [www.LLS.org/WhatToAsk](http://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 treatment should begin?
  - 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 at (800) 955-4572 to discuss a way that makes you comfortable. You may also want to check with your insurance to ensure that a second opinion will be covered.



## Before-Treatment Considerations

Adults who have CML and may want to have children in the future, and parents of children who have CML, should ask the doctor about ways to lessen the risk of infertility (inability to have children).

**Here are some questions you may want to ask your healthcare team.**

Below are a few questions. See pages 46-49 for a full list of questions in this Guide.

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 have to make decisions?

### WANT MORE INFORMATION?



You can view, print or order the free LLS fact sheet *Fertility Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists at (800) 955-4572 for a copy.

## About CML Treatments

New treatments may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://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 participation in a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. By considering all of your treatment options, including clinical trials, you will be taking an active role in the very important decision-making process that affects you.

A patient's treatment plan depends on a number of factors including the phase of CML at diagnosis, test results and patient age. For a list of drugs used to treat CML, see *Some Drugs Used to Treat CML* on page 21.

**Tyrosine Kinase Inhibitor (TKI) Drug Therapy.** Tyrosine kinase inhibitors (TKIs) are a type of targeted therapy that are taken by mouth. TKIs have

changed CML from a potentially deadly cancer to one that can be controlled with medication. However, not all patients respond to TKIs. Five TKIs have been approved for use to date.

The first therapy given for a disease is called “initial treatment” or “first-line treatment.” To date, four TKI drugs are approved as initial therapy for chronic phase CML:

- Imatinib mesylate (Gleevec®)
- Dasatinib (Sprycel®)
- Nilotinib (Tasigna®)
- Bosutinib (Bosulif®)

For some patients, the first TKI may not work because of unbearable side effects or because of drug resistance (when the cancer does not respond to treatment). If the initial TKI does not work, a second TKI is tried. If both the initial and second-line TKIs do not work, a third TKI can be offered to the patient. In case of resistance and/or intolerance to second-line treatments, other TKI options are:

- Ponatinib (Iclusig®)
- Asciminib (Scemblix®)

**Note:** Imatinib mesylate, dasatinib, nilotinib, bosutinib, ponatinib and asciminib work in different ways to block the protein produced by the *BCR::ABL1* cancer gene. When taking any of these drugs, it is important to:

- Take the prescribed amount of medication each day to maintain the response to treatment.
- Follow the doctor’s instructions for taking your medication—the instructions for taking TKIs may all be different.
- Get regular checkups for CML. Blood tests—and from time to time, bone marrow tests—are needed.

For each drug’s prescribing information, please see *Some Drugs Used to Treat CML* on page 21.

Generic versions of TKIs have been available since 2016. A generic drug is a medication created to be the same as a brand-name drug that is already on the market. A generic medicine works in the same way and provides the same benefit as its brand-name version. In other words, you can take a generic medicine as an equal substitute for its brand-name counterpart. The FDA has strict standards to ensure that generic drugs are the same

as brand name drugs in the United States. Talk to your doctor about which treatment option is best for you.

**Side Effects of TKIs.** The term side effect is used to describe the ways that treatment may affect healthy cells and the body in general.

Many treatment side effects go away or become less noticeable over time. Most can be handled without the need to stop the drug; however, changing to another treatment may be an option to decrease side effects and increase quality of life. Talk to your doctor about the possible side effects and long-term effects of your treatment.

Here are some questions to begin a discussion with your healthcare team.

- How can I best talk with my healthcare team about the treatment's impact on my quality of life?
- What changes can safely be made with my current treatment to reduce my side effects?
- Are there other changes I can make to the way I take my medication that might make my side effects easier? (Examples include dissolving the pill in juice, avoiding taking it before lying flat in bed at night, splitting up the dose, etc.)
- What are the long-term side effects of my current treatment?
- When should I think about changing my treatment based on side effects and how my treatment is affecting my daily activities?
- Are there any tools or tips to help me track my side effects and the impact on my quality of life?
- If I switch medications but find the new one less tolerable, can I go back on my current medication?

At your regular check-ups, your doctor should check you for side effects of the drug you are taking. For information, you can also call our Information Specialists at (800) 955-4572.

**Imatinib mesylate (Gleevec®).** Common side effects may include:

- Rash
- Muscle cramps
- Diarrhea
- Nausea and vomiting
- Low blood cell counts

**Dasatinib (Sprycel®).** Common side effects may include:

- Headache
- Feeling tired
- Diarrhea
- Rash
- Nausea
- Low blood cell counts
- Fluid around the lungs or the heart

**Nilotinib (Tasigna®).** Common side effects may include:

- Nausea, vomiting, diarrhea
- Rash
- Feeling tired
- Constipation
- Cough
- Itching
- Muscle and joint pain
- Low blood cell counts

**Bosutinib (Bosulif®).** Common side effects may include:

- Fluid retention
- Rash
- Diarrhea
- Feeling tired
- Low blood cell counts

**Ponatinib (Iclusig®).** Common side effects may include:

- Rash
- Stomach pain
- Feeling tired
- Headache
- Dry skin
- High blood pressure
- Low blood cell counts

**Asciminib (Scemblix®).** Common side effects may include:

- Feeling tired
- Muscle pain
- Rash
- Diarrhea
- Respiratory tract infections
- Low blood cell counts

**Cardiac Effects.** Patients treated with certain TKIs have sometimes, although rarely, developed cardiac issues. Most of the patients with these conditions have other health problems and risk factors, including older age and a medical history of cardiac (heart) disease. Your doctor should give you a list of medications to avoid, and will monitor you for these conditions as needed. Cardiac effects can include:

- Severe congestive heart failure (a weakness of the heart that leads to a buildup of fluid in the lungs and surrounding body tissues)
- Left ventricular dysfunction (difficulty emptying blood from the left lower chamber of the heart)

A possible side effect of nilotinib that needs to be regularly monitored is a heart rhythm condition called **QT prolongation**. Patients should avoid other medications that are known to cause QT prolongation.

**Other Rare Side Effects.** Dasatinib may increase the risk of a serious condition called **pulmonary arterial hypertension (PAH)**. This side effect appears to be rare. Nilotinib may be associated with an increased risk of vascular events (disease relating to blood vessels). Ponatinib is only for patients who cannot take any other TKI therapy because of an association with severe liver problems including liver failure. Talk to your doctor for more information about these rare side effects.

### WANT MORE INFORMATION?



You can view, print or order free LLS publications about side-effect management. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) and filter for Side Effect Management or contact our Information Specialists for copies.

**TKI Adherence.** It is very important for you to take your TKIs as prescribed by your doctor. Adherence to an oral therapy means that you:

- Take the correct dose of medication
- Take the medication at the correct time
- Never miss a dose
- Never take an extra dose
- Never take a dose with foods, liquids or other medications that are not allowed

In most patients, TKIs can control CML. You must take your medication as prescribed to achieve the best response. Do not skip doses to try to reduce the side effects of the medication. Tell your doctors about any side effects that you are experiencing. Your doctor can help you manage these side effects or discuss switching to another medication.

It is important for you to continue taking your medication. By not taking the treatment as prescribed, the medicine may not work the correct way and you will not get the best response.

**Chemotherapy.** Chemotherapy is generally used in patients only with blast phase CML in hopes of returning the disease to the chronic phase. Very high-dose chemotherapy is also sometimes used to prepare patients for an allogeneic stem cell transplantation. See *Some Drugs Used to Treat CML* on page 21.

**Omacetaxine mepesuccinate (Synribo®)** is a type of drug called a **protein synthesis inhibitor**. For FDA approval information, please see *Some Drugs Used to Treat CML* on page 21. Omacetaxine mepesuccinate is given by injecting the drug under the skin (subcutaneous injection).

Common side effects of omacetaxine mepesuccinate may include:

- Low blood cell counts
- Diarrhea
- Nausea
- Feeling tired
- Fever
- Infection
- Reaction at the injection site

## Some Drugs Used to Treat CML

Drug Name / Administration	Indication
Imatinib mesylate (Gleevec®) given by mouth	<ol style="list-style-type: none"> <li>1. Newly diagnosed adults with Ph+ CML in chronic phase</li> <li>2. Patients with Ph+ CML in chronic, accelerated or blast phase, after failure of interferon-alfa therapy</li> <li>3. Newly diagnosed children with Ph+ CML in chronic phase</li> </ol>
Dasatinib (Sprycel®) given by mouth	<ol style="list-style-type: none"> <li>1. Newly diagnosed adults with Ph+ CML in chronic phase</li> <li>2. Adults in chronic, accelerated or blast phase Ph+ CML with resistance or intolerance to prior therapy including imatinib</li> <li>3. Pediatric patients aged 1 year and older with Ph+ CML in chronic phase</li> </ol>
Nilotinib (Tasigna®) given by mouth	<ol style="list-style-type: none"> <li>1. Newly diagnosed adults with Ph+ CML in chronic phase</li> <li>2. Adults in chronic or accelerated phase Ph+ CML with resistance or intolerance to prior therapy that included imatinib</li> <li>3. Newly diagnosed pediatric patients aged 1 year and older with Ph+ CML in chronic phase</li> <li>4. Pediatric patients aged 1 year and older with Ph+ CML in chronic phase or accelerated phase with resistance or intolerance to prior TKI therapy</li> </ol>
Bosutinib (Bosulif®) given by mouth	<ol style="list-style-type: none"> <li>1. Newly diagnosed adults with Ph+ CML in chronic phase</li> <li>2. Adults in chronic, accelerated or blast phase Ph+ CML with resistance or intolerance to prior therapy</li> </ol>
Ponatinib (Iclusig®) given by mouth	<ol style="list-style-type: none"> <li>1. Chronic phase CML with resistance or intolerance to at least two prior kinase inhibitors</li> <li>2. Accelerated phase or blast phase CML for whom no other kinase inhibitors are indicated</li> <li>3. T315I-positive CML (chronic phase, accelerated phase, or blast phase)</li> </ol>
Asciminib (Scemblix®) given by mouth	<ol style="list-style-type: none"> <li>1. Adult patients with Ph+ CML in chronic phase, previously treated with two or more tyrosine kinase inhibitors (TKIs)</li> <li>2. Adult patients with Ph+ CML in chronic phase with the T315I mutation</li> </ol>
Omacetaxine mepesuccinate (Synribo®) given subcutaneously	Adults in chronic or accelerated phase CML with resistance and/or intolerance to two or more TKIs

**The following drugs were used as initial therapy before TKIs were introduced. They may continue to be used in select patients.**

- Interferon alfa (Roferon®-A)
- Pegylated interferon alfa
- Hydroxyurea (Hydrea®)
- Cytarabine (Cytosar-U®)
- Busulfan (Myleran®)

**Stem Cell Transplantation.** Your doctor will talk to you about whether stem cell transplantation is a treatment option for you. Most people with CML have a good response to drug treatment, which may be able to control CML for a very long time. But in some cases, allogeneic stem cell transplantation may be used to treat CML.

**Allogeneic Stem Cell Transplantation.** This is a procedure in which stem cells from another person (a donor) are infused into your body. The donor may be a brother or sister. Or the donor can be an unrelated person with stem cells that “match” the patient’s. Stem cells may also come from donated cord blood (the blood in the umbilical cord after a baby’s birth).

The goals of an allogeneic transplant are to:

- Cure the patient of CML by killing remaining CML cells with high-dose chemotherapy
- Restore the body’s ability to make healthy blood cells

Before the transplant, the patient receives drugs to bring the disease under control. After the patient responds to this treatment, they are given high-dose chemotherapy and/or radiation to prepare the body to receive the donor cells. Stem cells are collected from a donor. The stem cells from the donor are given to the patient through an intravenous (IV) line or central line. The donor stem cells go from the patient’s blood into the patient’s bone marrow. They help start a new supply of healthy red blood cells, white blood cells and platelets. This procedure is done in the hospital.

Allogeneic stem cell transplantation is most successful in younger patients. However, there is no specific age cutoff for stem cell transplantation. It may be a good treatment for a younger CML patient who does not respond well to oral drug treatment and who has a matched stem cell donor.

Allogeneic stem cell transplantation is the only treatment that can cure CML. About 7 out of 10 people who have an allogeneic transplant



are cured of their CML. But this procedure has a high risk of serious complications. If a transplant is recommended for you, your doctor will explain the benefits and the risks.

**Reduced-Intensity Transplant.** Doctors are working to make allogeneic stem cell transplants safer. A type of transplant called a **reduced-intensity transplant** uses a lower dosage of chemotherapy than the dosage used with a standard allogeneic stem cell transplant. This treatment is also called a **nonmyeloablative transplant**. Older and sicker people may be helped by this treatment.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Blood and Marrow Stem Cell Transplantation* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for a copy.

## Treating CML by Phase

**Treatment for Chronic Phase CML.** For people with chronic phase CML, the goals of treatment are to:

- Return blood cell counts (red blood cells, white blood cells and platelets) to normal levels
- Kill all cells that have the *BCR::ABL1* cancer oncogene

TKI therapy is standard treatment for chronic phase CML. TKIs are often successful at managing CML for long periods of time. Four TKIs are approved as primary treatment for chronic phase CML:

- Imatinib mesylate (Gleevec®)
- Dasatinib (Sprycel®)
- Nilotinib (Tasigna®)
- Bosutinib (Bosulif®)

After the start of therapy, doctors will monitor your treatment response. If you are not responding well, the doctor will need to find out why. Gene mutation testing should be done (see page 24).

Options for treatment can include increasing the dosage (amount) of the current drug, switching to another TKI (for example, if you started on imatinib, you could switch to dasatinib, nilotinib, bosutinib, asciminib

(Scemblix®), or ponatinib (Iclusig®) or you could try another treatment like omacetaxine mepesuccinate (Synribo®).

Usually people being treated for chronic phase CML feel well. They can go about their day-to-day activities. However, if the side effects of the treatment are decreasing your quality of life, speak to your doctor.

**Treatment for Accelerated Phase CML.** The goal in treating accelerated phase CML is to kill all cells that contain the *BCR::ABL1* gene, leading to a remission. If this is not possible, the goal is to return the disease back to the chronic phase.

In accelerated phase CML, the cancer cells often have new genetic mutations that may make treatments less effective. Patients should have *BCR::ABL1* gene mutation testing (see below) before starting treatment to find out which treatment option is best for them.

Dasatinib, nilotinib, bosutinib and ponatinib are effective treatments for people who have accelerated phase CML. Other options include:

- Treatment in a clinical trial (see page 28)
- The drug omacetaxine mepesuccinate for patients who have experienced resistance or intolerance to two or more TKIs
- Allogeneic stem cell transplantation

**Treatment for Blast Phase CML.** Patients with blast phase CML have leukemia cells that have become very abnormal. Patients with blast phase CML have higher blood counts and more severe symptoms. Treatment at a specialized center with doctors who have expertise in CML is recommended for patients in the blast phase of the disease. Patients' cancer cells will need to be tested for different mutations (see below).

One option for patients with blast phase CML is to receive treatment within a clinical trial. Another treatment option is for patients to receive TKI therapy, with or without chemotherapy, and then proceed to an allogeneic stem cell transplant.

## Gene Mutation Testing

Gene mutation testing may help find changes in a *BCR::ABL1* cancer gene. The test should be ordered if there is:

- A treatment milestone the patient does not meet

- Loss of hematologic, cytogenetic or major molecular response despite taking an appropriate dose of a TKI (see *Measuring Treatment Response* on pages 29-30)
- An unexplained rise in CML cells as shown on a qPCR test
- Concern that the medication is not working

The results of a mutation test may tell the doctor why one drug may work and another may not. A mutation test does not need to be done for a patient who is switching medication because of side effects.

Patients should talk to their doctor about ordering a mutation test and sending a blood sample to a reference laboratory (used for specialized tests). For information about the CML mutation testing guidelines from the National Comprehensive Cancer Network (NCCN), please visit [www.nccn.org](http://www.nccn.org).

## Financial Concerns

CML patients have many medication options but have to continuously take these drugs. This can make it hard for patients to pay for their medications. Patients can speak to their healthcare team if they have any concerns about being able to pay for their medications.

Organizations, foundations and prescription assistance programs can help patients find ways to pay for their prescription drugs. In addition, several major pharmaceutical manufacturers provide patient assistance or prescription assistance programs. These companies may be able to help by providing both insured and uninsured patients with either free or reduced-cost medications.

You can contact an LLS Information Specialist at (800) 955-4572 for information about our Co-Pay Assistance Program and other financial assistance programs.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Cancer and Your Finances* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for a copy.

## Children and Young Adults With CML

A small percentage of patients diagnosed with CML are children and young adults. CML represents about 2 percent of newly diagnosed childhood leukemias.

Specific guidelines for CML treatment in children have yet to be determined. Treatment in children often follows guidelines developed for adults.

Children with CML should be treated by pediatric hematologist-oncologists (doctors who specialize in treating children with blood cancers).

The following TKIs are used in the treatment of children with CML:

- Imatinib mesylate (Gleevec®)
- Dasatinib (Sprycel®)
- Nilotinib (Tasigna®)

There is evidence that TKI drugs may slow growth in children, particularly for those treated before they reach puberty. Careful monitoring of the child's height and overall growth, thyroid function and heart during treatment is recommended.

With oral medications, it is important to follow the doctor's directions and ensure that the child takes the medication for as long as prescribed. This can be difficult not only for parents of younger children, but also for teens and young adults, because remembering to take the drug can be hard.

Talk to your child's doctor about the best treatment for your child and any concerns you may have regarding their treatment.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Choosing a Blood Cancer Specialist or Treatment Center* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies. Please visit [www.LLS.org/FamilyWorkbook](http://www.LLS.org/FamilyWorkbook) for information about coping with a blood cancer.

## Pregnancy, Fertility and TKIs

Many CML patients of childbearing age living with stable remissions are considering having children while taking TKIs. Generally, there are no concerns associated with having children for males who are taking TKIs.

However, for female patients who want to become pregnant, the issues are more complex. TKIs including imatinib mesylate, dasatinib and nilotinib may result in abnormalities to the fetus or miscarriages. Females should consult with their hematologist-oncologist and a high-risk obstetrician to discuss the potential risks of stopping TKI therapy during pregnancy versus the risks of continuing TKI therapy during pregnancy.

Doctors continue to study how CML treatment affects pregnancy. For more information, speak with your doctor so that you understand the:

- Need to stop treatment during preconception (before you become pregnant) and pregnancy
- Risk of relapse, if therapy is stopped
- Risk for fetal effects from TKI drugs (probably greatest during the first trimester)
- Need for females on TKI therapy to refrain from breastfeeding their babies
- Uncertainty about treatment options and getting a stable response during and after pregnancy

Treatment-free remission is now an emerging treatment goal for many patients with CML who have achieved a deep, stable response to treatment. Female patients who are interested in having children should discuss all their options with their treatment team, including the possibility of TKI discontinuation to try for treatment-free remission. See *Treatment-Free Remission* on page 31.

If you are on TKI therapy, it is important to talk to your doctor if you are thinking about having a child.

## PART 3 Clinical Trials

### About Clinical Trials

Doctors may recommend that a patient join a clinical trial. Clinical trials are careful studies done by doctors to test new drugs or treatments or new uses for approved drugs or treatments. For example, changing the amount of the drug or giving the drug along with another type of treatment might be more effective. Some clinical trials combine drugs for CML in new sequences or dosages.

There are clinical trials for:

- Newly diagnosed CML patients
- Patients who do not have a good response to treatment (refractory disease)
- Patients who relapse after treatment

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

**Here are some questions you may want to ask your healthcare team.**

See pages 46-49 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 is 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. 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](http://www.LLS.org/CTSC) for more information.

#### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

## PART 4 Treatment Response and Follow-Up Care

### Overview

- After you begin treatment, your doctor will regularly order blood and bone marrow tests to see how well treatment is working.
- It is very important to measure your response to treatment. The results are used to help your doctor determine if your CML is well controlled.
- CML follow-up care varies from patient to patient, but you will need to see your doctor on a regular basis to evaluate your health.

#### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Chronic Myeloid Leukemia* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

### Measuring Treatment Response

After you begin treatment, your doctors will regularly order blood and bone marrow tests to see how well the treatment is working. In general, the greater the response to drug therapy, the longer the disease will be controlled. The results are used to help your doctor decide if your CML is well controlled or if there is a need to:

- Increase the dose to try for a better response
- Decrease or stop the drug briefly because of side effects
- Change to a different drug to better control the CML
- Change to a different drug to manage side effects

There are three types of responses: hematologic, cytogenetic and molecular. *Treatment Response* on page 30 explains the different types of treatment responses for CML.

Most people with chronic phase CML have a complete hematologic response with TKI drugs. Most of these individuals go on to have a complete cytogenetic response. Many may also have a major or deep molecular response.

Information about what you can do to keep track of your CML tests is included on page 11.

## Treatment Response

### Hematologic Response

A complete hematologic response means that the numbers of white blood cells, red blood cells and platelets are normal or near normal.

**The Test:** A complete blood count (CBC) is done to measure the numbers of white blood cells, red blood cells and platelets, and the levels of hemoglobin (a protein in red blood cells that carries oxygen) and hematocrit (the amount of red blood cells in the total blood volume).

### Cytogenetic Response

A complete cytogenetic response means that there are no cells with the Ph chromosome detected in the bone marrow.

**The Test:** A qPCR test measures the number of cells that have the *BCR::ABL1* cancer gene in the blood. Either cytogenetic analysis or a FISH test is used if a reliable qPCR test is not available.

### Molecular Response

A molecular response is a decrease in the number of cells with the *BCR::ABL1* cancer gene in the blood. A patient's molecular response is important in predicting outcomes and in determining future treatments.

- In an **early molecular response**, no more than 10 percent of cells (10 out of every 100 cells) have the *BCR::ABL1* cancer gene in the blood.
- In a **major molecular response (MMR)**, no more than 0.1 percent (1 out of 1,000 cells) have the *BCR::ABL1* cancer gene.
- In a **deep molecular response (DMR)**, no more than 0.01 percent (1 out of 10,000 cells) have the *BCR::ABL1* cancer gene.
- In a **undetectable/complete molecular response (CMR)**, no cells with *BCR::ABL1* cancer gene are found.

**The Test:** A qPCR test measures the number of cells that have the *BCR::ABL1* cancer gene in the blood. If possible, the same laboratory should be used for qPCR testing each time. This is because the results may vary from lab to lab.



## Treatment-Free Remission

Treatment-free remission (TFR) is achieved when patients can safely stop taking their TKI medications and still continue to have a deep molecular response. Because of the better understanding of CML and the successful results of TKI therapy, TFR is thought to be a main goal of treatment for CML patients. Patients in the chronic phase of CML who have had a good and deep molecular response for at least two years are considered candidates for stopping TKI therapy under careful medical supervision.

Talk to your doctor to see whether trying treatment-free remission may be a potential option in your case. **It is important to consult with an experienced CML doctor before attempting treatment-free remission.**

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Chronic Myeloid Leukemia* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies.

## Follow-Up Care

Medical follow-up is important for every CML patient. Follow-up care helps your doctor see how well your treatment worked and is still working, and to determine if different treatment is needed.

Patients should see their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. Ask your doctor about how often you should have follow-up visits. You can also ask the doctor what tests will be needed and find out how often you need to have these tests. It is important to get and keep a record of your cancer treatment, including the drugs you receive 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 43 for a place that you can list your treatments.

**Here are some questions you may want to ask your healthcare team.**

See pages 46-49 for a full list of questions.

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

Follow-up care includes physical exams and blood tests. Sometimes bone marrow tests are also needed. For CML patients, qPCR testing is initially recommended every 3 months. After 2 years of achieving and maintaining a *BCR::ABL1* level of 1 percent or less, the test should be done every 3 to 6 months.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Navigating Life During and After a Blood Cancer Diagnosis* at [www.LLS.org/booklets](http://www.LLS.org/booklets) or contact our Information Specialists for copies. There are versions for adults, young adults, and children and adolescents.

## Take Care of Yourself

- Keep all your doctors' appointments (specialists, primary care, testing).
- Talk with the doctor about how you feel at each visit.
- Ask any questions you may have about side effects.
- People with CML may have more infections. Follow your doctor's advice for preventing infection.
- Eat healthy foods each day. It may help to eat 4 or 5 smaller meals instead of 3 larger ones.
- Contact your doctor if you feel tired, have a fever, or experience other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Check 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 your healthcare needs.
- Talk with family and friends about how you feel and about your treatment. When family and friends know about CML and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. If you feel sad or depressed every day for a 2-week period, seek help. Depression is an illness. It should be treated even when a person is being treated for CML. 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 lists various resources you may find helpful.

### For Help and Information

**Consult with an Information Specialist.** Information Specialists can assist you through cancer treatment and financial and social challenges and give accurate, up-to-date disease treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: [www.LLS.org/InformationSpecialists](http://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. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Nutrition Consultations.** Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients of all cancer types and their caregivers. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Free Information Booklets.** LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://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](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical

expenses like travel, food, utilities, housing, etc. For more information, please:

- Call: (877) 557-2672
- Visit: [www.LLS.org/finances](http://www.LLS.org/finances)

**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](http://www.LLS.org/TheBloodline) for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

**3D Models.** LLS offers interactive 3D images to help visualize and better understand blood cell development, intrathecal therapy, leukemia, lymphoma, myeloma, MDS, MPNs and lab and imaging tests. Visit [www.LLS.org/3D](http://www.LLS.org/3D) for more.

### **Free Mobile Apps.**

- **LLS Coloring For Kids™** — Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit [www.LLS.org/ColoringApp](http://www.LLS.org/ColoringApp) to download for free.
- **LLS Health Manager™** — Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit [www.LLS.org/HealthManager](http://www.LLS.org/HealthManager) to download for free.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

## **Connecting with Patients, Caregivers and Community Resources**

**LLS Community.** At this one-stop virtual meeting place you can talk with other patients and receive 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](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**Local Programs.** 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 region, please:

- Call: (800) 955-4572
- Visit: [www.LLS.org/LocalPrograms](http://www.LLS.org/LocalPrograms)

**Advocacy and Public Policy.** Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit [www.LLS.org/advocacy](http://www.LLS.org/advocacy) for more information.

**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](http://www.LLS.org/ResourceDirectory) to view the directory.

### **Additional Help for Specific Groups**

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://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](http://www.publichealth.va.gov/exposures/AgentOrange)

**Information for Firefighters.** Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit [www.LLS.org/FireFighters](http://www.LLS.org/FireFighters) for resources and information.

**World Trade Center Health Program.** 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](http://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 2-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](http://www.nimh.nih.gov) and enter “depression” in the search box

## Health Terms

**Anemia.** A condition in which a person has fewer red blood cells than normal.

**Blast cell.** Immature bone marrow cell. About 1 to 5 percent of normal bone marrow cells are blast cells.

**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 bone marrow and the cells are looked at under a microscope.

**Bone marrow biopsy.** A procedure to remove and examine bone 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 or drug therapy.** Treatment that stops the growth of cancer cells, either by killing the cancer cells or by stopping them from dividing.

**Chromosomes.** Threadlike structures within cells that carry genes. Human cells have 23 pairs of chromosomes. The number or shape of chromosomes may be changed in blood cancer cells.

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

**Diagnose.** To detect a disease based on a patient's signs, symptoms and test results. The doctor diagnoses a disease in a patient.

**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.

**FISH.** The short name for fluorescence in situ hybridization, a test for studying abnormal genes and chromosomes in cells and tissues.

**Hematocrit.** The amount of red blood cells in the total blood volume.

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

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

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

**Karyotype.** An organized “map” of a person’s chromosomes. It exhibits the size, shape and number of chromosomes in a sample of cells.

**Leukemia.** A cancer of the blood and bone marrow.

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

**Oncologist.** A doctor with special training for treating people who have cancer.

**Plasma.** The liquid part of the blood.

**Platelet.** A type of blood cell that helps prevent bleeding. Platelets cause plugs (“clotting”) to form in the blood vessels at the site of an injury.

**qPCR.** The short name for quantitative polymerase chain reaction, a sensitive lab test that can measure the presence of cancer cell markers in the blood or bone marrow. The qPCR test is used to detect remaining cancer cells that cannot be detected by other tests.

**Red blood cell.** The 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 blood.

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

**Relapsed CML.** CML that responded to treatment at first, but then returned.

**Remission.** A state in which there is no sign of the disease and/or a period of time when the disease is not causing any health problems.



**Resistance.** When a drug does not work or stops working.

**Stem cell.** A type of cell found in the bone marrow that will mature into a red blood cell, white blood cell or platelet.

**Tyrosine kinase inhibitor (TKI).** A drug that blocks cell growth. TKIs are used to treat CML.

**White blood cell.** A type of blood cell 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: [infocenter@LLS.org](mailto:infocenter@LLS.org)**

**Website: [www.LLS.org/InformationSpecialists](http://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 decision.)

### 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:

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1. How long will 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](http://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:

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Write down your phase of CML:

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## 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 phase?
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 all right 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 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 lifelong follow up?
2. Will I (we) continue to see this healthcare team?
3. How can I 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 have side effects later, how can the healthcare team be reached?
6. What information can be provided to my primary doctor about my treatment?

**To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://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 and nurses who are available by phone, email and live chat 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
- Get connected to resources

Contact us at  
**800.955.4572**  
or **www.LLS.org/**  
**InformationSpecialists**

(Language interpreters  
can be requested.)



For more information, please  
contact our Information Specialists  
**800.955.4572** (Language interpreters  
available upon request).

**National Office** 3 International Drive, Suite 200 Rye Brook, NY 10573

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