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CML: The Basics

A companion to Chronic Myeloid Leukemia: In Detail

Revised **2025**

Formerly titled The CML Guide:
Information for Patients and Caregivers

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INTRODUCTION

Chronic myeloid leukemia (CML) is a type of blood cancer in which the bone marrow makes too many white blood cells called granulocytes. It is also known as chronic myelogenous leukemia, chronic granulocytic leukemia and chronic myelocytic leukemia.

Since 2001, drugs called tyrosine kinase inhibitors (TKIs) have been approved to treat CML. For most people with CML, TKIs have changed CML from a life-threatening illness to a chronic disease that can be controlled but not cured. People with CML are now living longer and experiencing fewer treatment side effects.

The more you know about your disease, the better you can take care of yourself—your mind, your body and your health. This booklet provides information about the diagnosis, staging and treatment of CML. It also includes brief descriptions of normal blood and bone marrow, as well as a glossary of health terms related to CML.

We hope that you will keep this booklet handy and that, should you ever feel alone in confronting problems, you will turn to it for information and guidance to find the support and resources you need.

We are here to help.

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

WANT MORE INFORMATION?

For more detailed information about CML, you can view, print or order the free LLS booklet *Chronic Myeloid Leukemia: In Detail* at www.LLS.org/booklets or call our Information Specialists at (800) 955-4572 for a copy.

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

PART 1 Chronic Myeloid Leukemia

Overview

- Chronic myeloid leukemia (CML) is a type of cancer of the blood and bone marrow. Chronic means that the leukemia is typically slow growing.
- Most blood cells are made in the bone marrow, the soft, spongy tissue in the center of bones. They begin as stem cells that go through many changes to develop into healthy red blood cells, white blood cells and platelets. Then they leave the bone marrow and enter the bloodstream.
- CML starts with a mutation (change) 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 booklet.

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 cells: red blood cells, white blood cells and platelets. After the blood cells have matured, they leave the bone marrow and 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. A low white blood cell count may cause repeated infections. There are two major types of white blood cells: lymphocytes and germ-eating cells.

- Lymphocytes are infection-fighting cells. The three types are:
  - B cells
  - T cells
  - NK cells
- Germ-eating cells kill and ingest bacteria and viruses. The two types are:
  - Neutrophils
  - Monocytes

Platelets help stop bleeding by clotting (clumping together) at the site of an injury. Low platelet counts may cause unexplained bruising and bleeding.

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)

- Measures the amount (percentage) of each of the different type of white blood 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 in the blood

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.

Causes and Risk Factors of CML. CML is a type of blood cancer that begins in the bone marrow. CML starts with a change to a single stem cell in the bone marrow. This means:

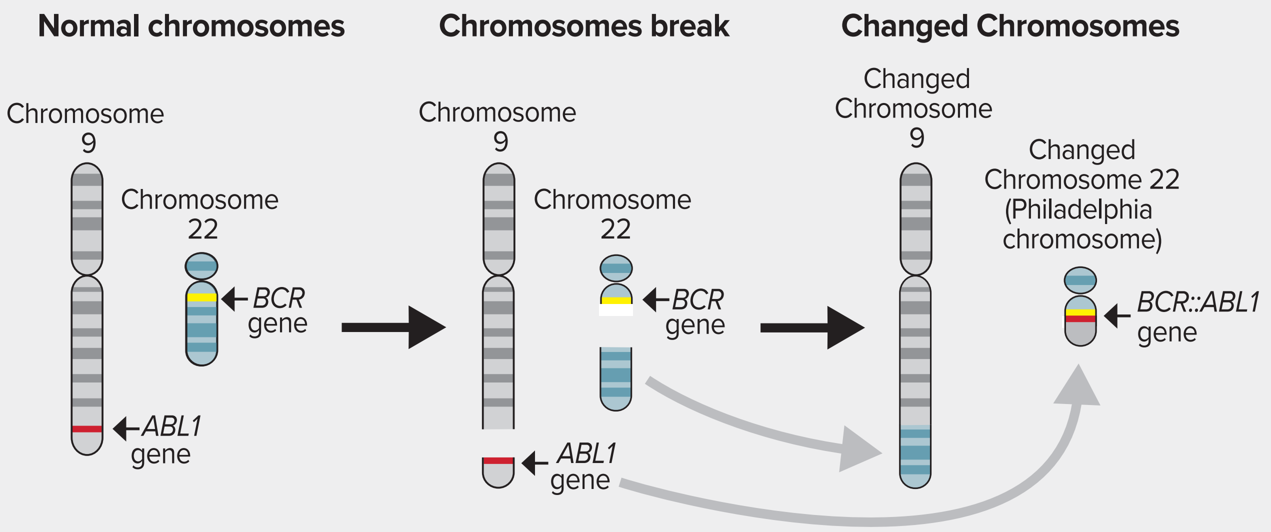
- A normal stem cell mutates (changes into a leukemia cell, also called a CML cell)
- The mutated cell multiplies into many CML cells
- The CML cells build up in the bone marrow so there is less room for healthy blood cells to develop. As a result, people with CML may not have enough healthy red blood cells, white blood cells and platelets.
- Over time, the CML cells spill out of the bone marrow into the bloodstream. This causes high white blood cell counts, but the CML cells do not work like normal white blood cells. As a result, people with CLM usually have weakened immune systems. Once the CML cells are in the blood, they can spread to other parts of the body such as the spleen, causing swelling and pain.

CML happens when there is a change in the the chromosome of a bone marrow cell. In human cells, the genetic information is contained in chromosomes. Most human cells have 23 pairs of chromosomes for a total of 46 chromosomes. Chromosomes are made of DNA.

In CML, part of chromosome 9 attaches to chromosome 22, and part of chromosome 22 attaches to chromosome 9. As a result, chromosome 9 is longer than normal, and chromosome 22 is shorter than normal. The abnormal chromosome 22 is known as the Philadelphia chromosome.

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 called *BCR::ABL1*. This abnormal gene makes a protein that signals the body to make too many granulocytes (white blood cells). These granulocytes also have the abnormal *BCR::ABL1* gene and do not develop into normal white blood cells.

How the *BCR::ABL1* Cancer-Causing Gene Is Created



- A piece of the *ABL1* gene on chromosome 9 breaks off.
- A piece of the *BCR* gene on chromosome 22 breaks off.
- These two 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 some people develop the Philadelphia chromosome that leads to CML. There is no way to prevent CML. You cannot catch CML from someone else.

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.

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 an increased risk of CML.

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 doctor sees in an exam or test result. A symptom is a change in the body that a person can see or feel.

CML symptoms tend to develop slowly. An abnormal white blood cell count during a routine blood test is often the first sign of 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

The symptoms of CML may be like those of other blood disorders or medical conditions. If you have any of these symptoms, speak with your doctor to get a proper diagnosis.

Diagnosis

Many people with CML do not have symptoms when they are diagnosed. 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 45–50 for a full list of questions.

1. What kind of testing will be done to diagnose my disease?
2. How long does it take to get the results?

3. How will I find out the results?
4. How often will testing be needed to monitor my treatment?
5. Where will testing be done?

Blood Cell Counts. 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. People with CML usually have high or very high white blood cell counts. These are the leukemia cells in the blood. Their red blood cell count may be lower than normal, and their number of platelets may be higher or lower than normal.

Bone Marrow Tests. CML begins in the bone marrow. A diagnosis of CML is confirmed by removing samples of bone marrow cells. Bone marrow aspiration and bone marrow biopsy are different tests in which samples of bone marrow (liquid and solid) are removed from the back of the hip bone using special needles. The samples are then sent to the lab for examination. Additional tests will be done on the bone marrow samples to learn more information about the bone marrow cells.

How Are 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.

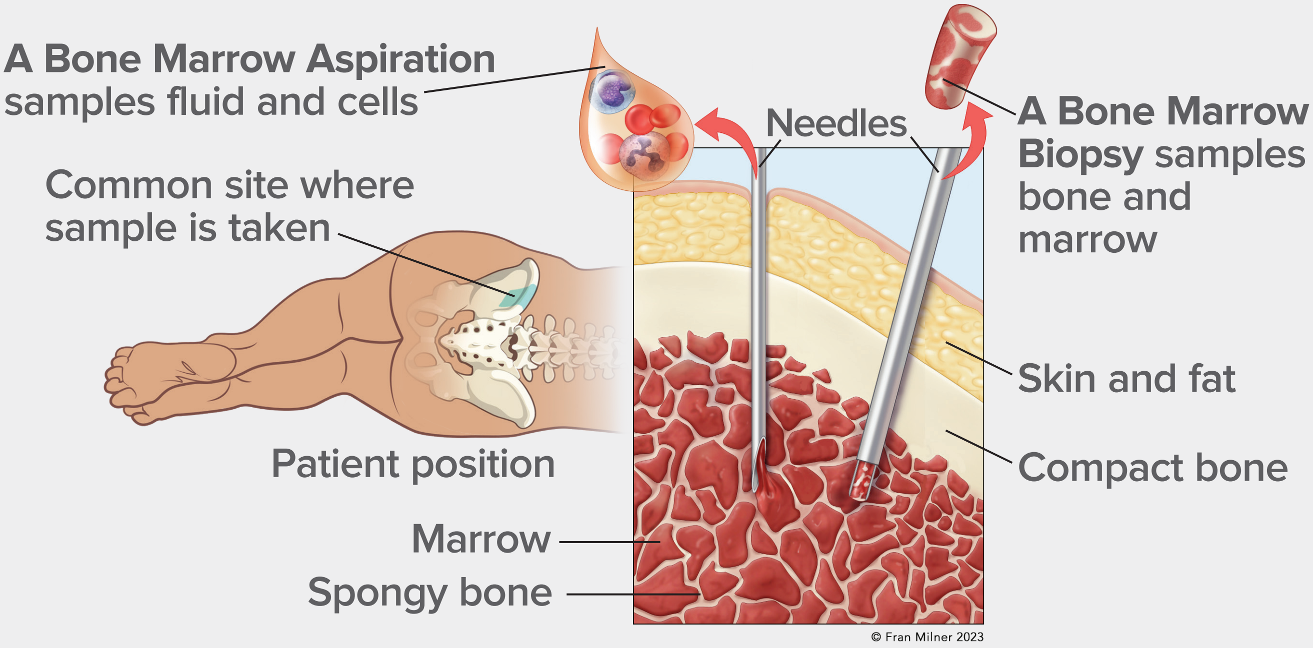
Bone Marrow Aspiration—A sample of fluid with cells is removed from the bone marrow.

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

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

Bone 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.

Bone Marrow Aspiration and Biopsy



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Left: The place on the back of the patient's hip bone where a bone marrow aspiration or biopsy is typically done. **Right:** One needle goes into the bone marrow to get a liquid sample for aspiration (the needle on the left) and the other needle goes inside the bone for a bone marrow biopsy (the needle on the right). The needle for the aspiration is thinner than the one for the biopsy.

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

Biomarker Testing. These laboratory tests check for changes in the proteins, genes and chromosomes of the cancer cells. Each person's cancer has a unique pattern of biomarkers. Biomarker testing is used to help diagnose CML and plan treatment.

Cytogenetic Testing. Samples of blood or bone marrow cells are examined under a microscope to look for changes in the chromosomes of the cells including translocations. The Philadelphia chromosome in a CML cell usually can be detected with cytogenetic testing. The presence of the Philadelphia chromosome is important information that—along with high white blood cell counts—helps the doctor diagnose CML.

Fluorescence In Situ Hybridization (FISH). This test is used to look at the genes and chromosomes in cells and tissues. FISH can detect CML cells that may not show up on standard cytogenetic testing.

Quantitative Polymerase Chain Reaction (qPCR). This sensitive test can detect a very small number of CML cells in a blood or bone marrow sample. qPCR is used to monitor how well treatment is working.

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 how to get copies of your lab reports. You can ask for copies of your test results at the doctor's office. Many hospitals and treatment centers now offer digital patient portals where you can view your medical records online.
○ 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 publications *Understanding Lab and Imaging Tests, Biomarker Testing for Cancer Treatment* and *Understanding Genetics.* Go to www.LLS.org/booklets or call our Information Specialists at (800) 955-4572 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. Leukemias such as CML are staged differently because they do not usually form tumors that can be measured. Instead, the stages of CML are based on the blood cell counts in the blood and bone marrow.

CML is categorized into three groups called phases. Knowing your phase of CML helps your doctor 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 in the United States are diagnosed with chronic phase CML. They have have increased white blood cells in the blood and bone marrow. If they have any symptoms, they are usually mild. 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 can progress to accelerated or blast phase CML.

Accelerated Phase CML. The number of leukemia cells in the blood and bone marrow is higher than in chronic phase CML. People with accelerated phase CML may have symptoms such as fever, weight loss, fatigue (extreme tiredness), bone pain and night sweats. If CML is not treated, it will progress to the next, more serious, blast phase.

Blast Phase (Also Called Blast Crisis Phase) CML. The number of leukemia cells in the blood and bone marrow is higher than in accelerated phase CML. People who have blast phase CML may have symptoms such as fever, fatigue, shortness of breath, abdominal pain, bone pain, enlarged spleen, poor appetite and weight loss, night sweats, bleeding and/or infections. Blast phase CML behaves like an acute (fast growing) form of leukemia.

Overview

- People with CML should choose a doctor who specializes in treating CML. 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 47–50.
- Some cancer treatments may affect fertility (the ability to have a child). If you want children in the future, or if you are the parent of a child with CML, talk with the doctor about which 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 right dose at the correct time can affect how well 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 blood disorders. 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 your cancer specialist to consult with a hematologist-oncologist 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 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.

Here are some questions you may want to ask your healthcare team. See pages 45–50 for a full list of questions.

1. How many patients have you treated with CML?
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 booklet *Choosing a Specialist or Treatment Center* at 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 45–50 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 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. Ask the doctor and staff if you can record the conversation (cell phones have a "record" function; ask someone how to use it if you are not sure).
- 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 a second opinion (another 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 is covered.

Before-Treatment Considerations

Fertility Concerns. Some cancer treatments may affect fertility (a person's ability to have children in the future). For adults who have CML and may want to have children in the future, and parents of children who have CML, it is important to talk with the doctor about whether the cancer treatments can affect fertility.

Here are some questions you may want to ask your healthcare team. See pages 45–50 for a full list of questions.

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 booklet *Fertility and Cancer* at 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 booklet 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 possible risks and benefits. It is important to think about all of your treatment options, including clinical trials. For more information on clinical trials, see page 29.

Tyrosine Kinase Inhibitor (TKI) Therapy. For most people with CML, treatment begins with a targeted therapy called a tyrosine kinase inhibitor (TKI). These drugs are taken orally (by mouth). TKIs have changed CML from a potentially deadly cancer to one that can be controlled with medication.

Each TKI has risks and benefits. Patients should talk with their doctor to determine which TKI to use. Choosing a TKI is based on many factors including:

- Patient age
- Pre-existing medical conditions such as diabetes or high blood pressure
- Phase of CML
- Additional chromosomal abnormalities or gene mutations in the CML cells
- Insurance coverage
- Out of pocket costs

To date, there are six TKIs that are approved to treat CML. They are:

- Asciminib (Scemblix®)
- Bosutinib (Bosulif®)
- Dasatinib (Sprycel®)
- Imatinib mesylate (Gleevec®)
- Nilotinib (Tasigna®, Danziten™)
- Ponatinib (Iclusig®)

For some patients, their first TKI may not work because of drug resistance (when the cancer does not respond to treatment). For others, the side effects may be unbearable. In either case, a second TKI is tried. If both the first and second TKIs do not work, a third TKI can be offered to the patient. For each drug's prescribing information, please see *Drugs Used to Treat CML* on pages 22–23.

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. Generic drugs typically cost less than brand-name versions. Talk to your doctor about whether a generic TKI is an option for you.

Side Effects of TKIs. Cancer treatments can cause side effects. Side effects are problems that occur when treatments affect healthy cells or organs in the body.

Each TKI has its own possible side effects. In some cases, they can be serious. Your doctor will monitor you for side effects. Tell your doctor if you notice any change that could be a side effect of your TKI. Most side effects can be handled without the need to stop the drug; however, changing to another TKI may be an option to decrease side effects and improve quality of life.

Here are some questions to begin a discussion with your doctor.

- ○ What changes can safely be made with my current TKI to reduce my side effects?
- ○ Can I change the way I take my TKI to help manage the side effects? (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 TKI?
- ○ When should I think about changing my TKI 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 my TKI but find the new one less tolerable, can I go back on my current medication?

At your regular check-ups, your doctor should ask if you are experiencing any side effects from your TKI. Some common side effects of TKIs include:

- ○ Feeling very tired
- ○ Headache
- ○ Rash
- ○ Muscle cramps
- ○ Diarrhea
- ○ Nausea and vomiting
- ○ Low blood cell counts
- ○ Muscle and joint pain

Cardiac (Heart) 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 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).

WANT MORE INFORMATION?

You can view, print or order free LLS publications about side-effect management. Visit www.LLS.org/booklets and filter for Side Effect Management or contact our Information Specialists at (800) 955-4572 for copies.

TKI Adherence. It is very important for you to take your TKI 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 TKI.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Oral Treatment Adherence Facts* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

TKI Resistance. Drug resistance is the term used when a disease is not responding to treatment. Drug resistance occurs when a patient is taking a TKI but the number of leukemia cells in their blood increases.

Sometimes resistance to a TKI can be overcome by increasing the dose of the TKI or by switching to another TKI. Before changing treatment, the doctor should determine if the patient is taking the TKI as prescribed and find out if the patient is taking other drugs that may interact with the TKI. For some, a TKI stops working if there is a new mutation in the CML cells. The doctor should check for new mutations in the *BCR::ABL1* gene (see *BCR::ABL1 Gene Mutation Testing* on page 26).

Drugs Used to Treat CML

For more information, see the package insert and/or the full prescribing information for each medication (available on the internet).

Drug Name/ Administration	Indications
Asciminib (Scemblix®) given by mouth	1. Adult patients with newly diagnosed Philadelphia chromosome-positive chronic myeloid leukemia (Ph+ CML) in chronic phase 2. Adults with previously treated Ph+ CML in chronic phase 3. Adult patients with Ph+ CML in chronic phase with the T315I mutation
Bosutinib (Bosulif®) given by mouth	1. Adult and pediatric patients 1 year of age and older with chronic phase Ph+ CML, newly diagnosed or resistant or intolerant to prior therapy 2. Adult patients with accelerated or blast phase Ph+ CML with resistance or intolerance to prior therapy
Dasatinib (Sprycel®) given by mouth	1. Newly diagnosed adults with Ph+ CML in chronic phase 2. Adults with chronic, accelerated or myeloid or lymphoid blast phase Ph+ CML with resistance or intolerance to prior therapy including imatinib 3. Pediatric patients 1 year of age and older with Ph+ CML in chronic phase
Imatinib mesylate (Gleevec®) given by mouth	1. Newly diagnosed adult and pediatric patients with Ph+ CML in chronic phase 2. Patients with Ph+ CML in blast crisis, accelerated phase, or in chronic phase after failure of interferon-alfa therapy

Drug Name/ Administration	Indications
Nilotinib (Tasigna®, Danziten™) given by mouth	Nilotinib (Tasigna®) 1. Adult and pediatric patients greater than or equal to 1 year of age with newly diagnosed Ph+ CML in chronic phase 2. Adult patients with chronic phase and accelerated phase Ph+ CML resistant to or intolerant to prior therapy that included imatinib 3. Pediatric patients greater than or equal to 1 year of age with Ph+ CML in chronic phase or accelerated phase resistant to or intolerant to prior TKI therapy …… Nilotinib (Danziten™) 1. Adult patients with newly diagnosed Ph+ CML in chronic phase 2. Adult patients with chronic phase and accelerated phase Ph+ CML resistant to or intolerant to prior therapy that included imantinib
Ponatinib (Iclusig®) given by mouth	1. Adults with chronic phase CML with resistance or intolerance to at least two prior kinase inhibitors 2. Adults with accelerated phase or blast phase CML for whom no other kinase inhibitors are indicated 3. Adults with T315I-positive CML (chronic phase, accelerated phase or blast phase)
The following drugs were used as initial therapy before TKIs were introduced and continue to be used in select patients: Interferon alfa (Roferon®-A, Intron® A) (immunotherapy) Pegylated interferon alfa (immunotherapy) Hydroxyurea (Hydrea®) (chemotherapy) Cytarabine (Cytosar-U®) (chemotherapy) Busulfan (Myleran®) (chemotherapy)	

Allogeneic Stem Cell Transplant. Some people with CML may benefit from an allogeneic stem cell transplant. While certain people with CML may be cured with an allogeneic stem cell transplant, not everyone can receive one. It is an intense treatment that can cause life-threatening side effects in some people. It is often not a good option for older patients or for patients who have other health problems.

An allogeneic stem cell transplant 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. Allogeneic transplants are done in the hospital. After a patient achieves a remission, the process of allogeneic transplant is as follows:

- Stem cells are collected from a donor, frozen and stored.
- The patient is given high-dose chemotherapy and/or radiation therapy.
- The donor stem cells are given to the patient through an intravenous (IV) line or central line.
- The donor stem cells go from the patient's blood to the bone marrow and begin making a new supply of red blood cells, white blood cells and platelets.

An allogeneic stem cell transplant may be a good treatment option for younger CML patients who do not respond to TKI therapy and who have a matched stem cell donor. While an allogeneic stem cell transplant is most successful in younger patients, there is no specific age cutoff for this treatment.

WANT MORE INFORMATION?

You can view, print or order the free LLS publication *Blood and Marrow Stem Cell Transplantation Guide* at www.LLS.org/booklets or call our Information Specialists at (800) 955-4572 for a copy or to ask questions.

Immunotherapy. Immunotherapy is a type of treatment that uses a person's own immune system to help fight cancer. Interferon, a type of immunotherapy, is a substance made naturally by the immune system, but it can also be made in the laboratory. Interferon can stop cancer cells from growing and dividing.

Before TKIs, interferon was considered the standard treatment for patients who were not candidates for an allogeneic stem cell transplant. Today, interferon therapy is rarely used as a treatment for CML because TKIs are more effective and have fewer side effects than interferon. But interferon may be an option for patients who cannot tolerate the side effects of TKI therapy or for patients who are pregnant.

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
- Eliminate all cells that have the *BCR::ABL1* gene

TKI therapy is standard treatment for chronic phase CML. The first therapy given for a disease is called first-line treatment. The following TKIs are approved as first-line treatment for chronic phase CML:

- Asciminib
- Bosutinib
- Dasatinib
- Imatinib
- Nilotinib

Some people with CML have a *BCR::ABL1* gene mutation called T315I. The following TKIs have been approved to treat CML with the T315I:

- Asciminib
- Ponatinib

After you start TKI therapy, your doctor will check to see if your treatment is working. If you are not responding well, the doctor will need to find out why. If you are taking your TKI as prescribed, and your treatment is not working, a *BCR::ABL1* gene mutation testing should be done to see if there are new mutations in the *BCR::ABL1* gene (see page 26).

If your first-line treatment does not work or stops working, your doctor may increase the dose of your current TKI or switch to another TKI (for example, if you started on imatinib, you could switch to dasatinib, nilotinib, bosutinib, asciminib or ponatinib).

Treatment for Accelerated Phase CML. The goal in treating accelerated phase CML is to eliminate 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.

Drugs used to treat accelerated phase CML may include bosutinib, dasatinib, nilotinib and ponatinib. Other options include:

- Treatment in a clinical trial (see page 29)
- Allogeneic stem cell transplant (see page 24)

Treatment for Blast Phase CML. Patients with blast phase CML have more leukemia cells in the blood and bone marrow and more severe symptoms. Treatment at a specialized center with doctors who have expertise in CML is recommended for patients with blast phase CML. 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 to receive TKI therapy and then proceed to an allogeneic stem cell transplant.

BCR::ABL1 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 30–31)
- An unexplained rise in CML cells
- 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.

Children and Young Adults With CML

CML is very rare in children. Because it is so rare, there are no standard treatment recommendations for children with CML. Children with CML should be treated by pediatric hematologist-oncologists (doctors who specialize in treating children with blood cancers).

The following TKIs are used to treat children with CML:

- Bosutinib
- Dasatinib
- Imatinib
- Nilotinib

There is evidence that TKIs 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 to ensure that the child takes the medication 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 difficult.

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 workbook *Caring for Kids and Adolescents with Blood Cancer* at www.LLS.org/FamilyWorkbook and visit www.LLS.org/ChildhoodYAresources for additional resources to help children and their families cope with a blood cancer. Or call (800) 955-4572 to contact our Information Specialists.

Pregnancy, Fertility and TKIs

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

However, for female patients who want to become pregnant, the issues are more complex. TKIs may result in abnormalities to the fetus or miscarriages. At present, no data suggest that any TKI can be taken safely during pregnancy. If treatment is needed during pregnancy, interferon is safe to use throughout 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

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 stopping TKI therapy. See *Treatment-Free Remission* on page 32.

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

Your doctor may recommend that you join a clinical trial. Clinical trials are careful studies done by doctors to test new drugs or treatments. Clinical trials study new uses for approved drugs or treatments, such as changing the dose of the drug or giving the drug along with another type of treatment or drug. Some clinical trials combine drugs 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 for you.

Here are some questions you may want to ask your healthcare team. See pages 45–50 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 throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for copies.

PART 4 Treatment Response and Follow-Up Care

Overview

- After you begin treatment, your doctor will regularly order 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 regularly.

Measuring Treatment Response

After you begin treatment, your doctors will regularly order blood tests to see how well your 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 31 explains the different responses.

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 deep molecular response.

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 blood cells with the *BCR::ABL1* cancer gene. 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 blood cells (10 out of every 100 cells) have the *BCR::ABL1* cancer gene.
- 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 or no more than .0032 percent (1 out of every 32,000 cells) have the *BCR::ABL1* gene.

The Test: A qPCR test measures the amount of *BCR::ABL1* that can be detected 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 is achieved when patients can safely stop taking their TKI medications and still continue to have a deep molecular response. Patients in the chronic phase of CML who have had a good and deep molecular response for at least 2 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: In Detail* at www.LLS.org/booklets for more information about treatment-free remission, or contact our Information Specialists at (800) 955-4572 for a copy.

Follow-Up Care

Medical follow-up is important for every CML patient. Follow-up care helps your doctor see how well your treatment is 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 how often you should have follow-up visits and what tests will be needed. 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 44 for a place that you can list your treatments.

Here are some questions you may want to ask your healthcare team.
See pages 45–50 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 0.1 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 survivorship workbook *Navigating Life During and After a Blood Cancer Diagnosis* at www.LLS.org/SurvivorshipWorkbook or contact our Information Specialists at (800) 955-4572 for a copy. There are versions for adults, young adults, and children and adolescents.

Take Care of Yourself

- ○ Keep all your doctor and lab appointments.
- ○ 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 four or five smaller meals instead of three larger ones.
- ○ Contact your doctor if you feel tired, have a fever or experience other symptoms.

- Keep a record of your cancer diagnosis, treatment and follow-up care needs. This is often called a survivorship plan. Share this information with any new doctors you see. The plan should include the following information:
    - A list of all healthcare providers
    - Diagnosis summary with specifics such as phase of CML and genetic markers
    - Treatment summary with specifics such as the names, dates and dosages of drugs, surgery and/or transplant information, response to treatment and side effects
    - 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 information
- 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.
- Talk to your doctor about pneumonia, flu, shingles, COVID-19 and other vaccines.
- 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.

Financial Concerns

CML patients are living longer, primarily because of the development of new and effective drugs. While this progress is exciting, the financial costs can become an obstacle to treatment. Paying for healthcare is a major concern for many people who are living with blood cancer. The high cost of cancer can lead to significant financial and emotional stress for both patients and their families.

Even if you have health insurance, cancer can still take a toll on your finances. You may have new expenses such as co-payments or travel for treatment. You may also have less income if you need to take time off from work.

Speak with your healthcare team if you have any concerns about being able to afford your treatment. They 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 many resources available to help with prescription drug payment. In addition, several major drug manufacturers currently provide patient assistance or prescription assistance programs. These programs can provide both insured and uninsured patients free or reduced-cost medications.

Call our LLS Information Specialists at **(800) 955-4572** for information about our financial assistance and medical debt case management programs for eligible patients.

WANT MORE INFORMATION?

You can view, print or order the free LLS publication *Cancer and Your Finances* at www.LLS.org/booklets or contact our Information Specialists at (800) 955-4572 for a copy.

Additional Resources

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam; to airborne hazards and burn pits while serving in Iraq, Afghanistan and other areas of Southwest Asia; to contaminated water at Camp Lejeune between 1953-1987; or to ionizing radiation during service may be able to get help from the United States Department of Veterans Affairs (VA). For more information, please

- Call: the VA (800) 749-8387
- Visit: https://www.va.gov/disability/eligibility/hazardous-materials-exposure/

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.

Mental Health. Caring for your mental health has benefits for cancer patients. Seek medical advice if you are struggling. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov

If you or your loved one is experiencing a mental health crisis, call 988 to talk to a trained mental health professional. The 988 Suicide and Crisis Lifeline is free, confidential and always available. For the Crisis Text Line, text HOME to 741741.

Other Helpful Organizations. The Leukemia & Lymphoma Society (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, visit www.LLS.org/ResourceDirectory to view the directory.

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: hwww.cdc.gov/wtc/faq.html

Health Terms

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

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. 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.

FDA. The short name for the US Food and Drug Administration. Part of the FDA's job is to ensure 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-Oncologist. A doctor who has special training in the diagnosis and treatment of blood cancers.

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

Immunotherapy. A treatment that stimulates or suppresses the immune system to help the body fight cancer.

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 (clots) 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.

Spleen. An organ that is located on the upper left side of the abdomen under the ribs and above the stomach. It filters the blood to help destroy microorganisms and get rid of old and damaged red blood cells.

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 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: ____________________

____

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:

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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 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 phase of CML:

____

____

____

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 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 or call (800) 955-4572.

NOTES

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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, 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**

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**

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

The Leukemia & Lymphoma Society Mail Center
1201 15th Street N.W., Suite 410, Washington, D.C. 20005

The mission of The Leukemia & Lymphoma Society (LLS) is to cure blood cancer and improve the quality of life of all patients and their families. Find out more at www.LLS.org.