



Chronic
Myeloid
Leukemia
CML



WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with chronic myeloid leukemia (CML). What does it mean and how will it affect you?

This fact sheet will help you:

Learn about CML
and how it is
diagnosed

Get an overview
of treatment
options

Understand
what happens
next

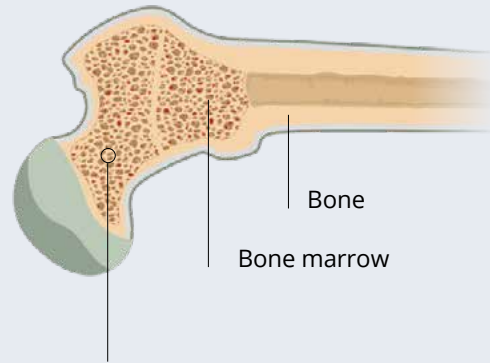
What is leukemia?

Leukemia is a cancer of the blood and bone marrow. Bone marrow is the soft, spongy material inside bones. Blood cells are formed in the bone marrow. Three kinds of blood cells develop from stem cells:

- Red blood cells carry oxygen
- White blood cells fight infection
- Platelets allow blood to clot

Although CML is a chronic cancer and cannot be cured, most people with CML are able to manage their symptoms over the long term.

Blood is created in the **bone marrow** (the spongy part inside the bone).



Stem cell



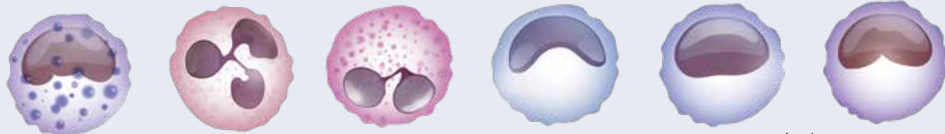
Three kinds of blood cells
develop from stem cells:



Red blood cells
(carry oxygen)



Platelets
(allow blood to clot)



White blood cells
(fight infection)

Lymphocytes
(create antibodies)

About CML

- CML is a rare type of leukemia (about 15% of all new cases of leukemia are CML)
- CML occurs when a person has a Philadelphia chromosome or another mutation which expresses a new gene (BCR-ABL) inside certain blood cells, causing the bone marrow cells to make too many white blood cells
- The Philadelphia chromosome is present in 95% of people with CML, but it is not passed from parent to child (it is not genetic)
- CML usually affects older adults (age 65+) and is more common in men

Symptoms of CML

CML develops slowly. There may be no obvious symptoms. CML is often discovered during a routine blood test, which may show a high white blood cell count. The large number of white blood cells crowds out other blood cells.

You may experience:

- Weakness, tiredness, and feeling out of breath during normal activity
 - When your red blood cell count is low (anemia)
- Fevers and night sweats
 - Possibly a response from your immune system
- Bone pain
 - When your white blood cells accumulate, causing your bone marrow to expand
- Weight loss
 - When you are eating less or using more energy
- Pain or a feeling of fullness below the ribs on the left side
 - When your CML cells build up in your liver or spleen, causing your abdomen to swell



Your diagnosis

With a diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how CML will likely progress and how you may respond to treatment. The results will determine if you are Philadelphia positive (Ph+) or negative (PH-).

You are not born with differences in genes and chromosomes that cause CML. In other words, being Ph+ is not genetic, or passed down from parent to child. Rather, these differences result accidentally, for no known reason, when blood cells are made in our bone marrow.

Here are some possible tests you may undergo:

Name of test	Description
Complete blood count (CBC)	This test measures the number of red blood cells, white blood cells, and platelets in a sample of blood.
Peripheral blood smear	This test looks at blood cells under a microscope to see the number, size, shape, type, and pattern of cells. It also measures the percentage of blast cells, a special type of cell found in higher quantities in someone with leukemia.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual (for example, abnormal numbers or types of blood-forming cells). They are usually done at the same time.
Cytogenetic analysis	This test looks for changes in chromosomes to help confirm CML.
FISH (fluorescence <i>in situ</i> hybridization)	This test looks at genes and chromosomes to find CML cells.
Quantitative polymerase chain reaction (qPCR)	The gene that causes CML is called BCR-ABL1. This test measures how much BCR-ABL1 is in the blood or bone marrow.
BCR-ABL1 kinase domain mutation analysis	This test looks for changes in the BCR-ABL1 gene to find out whether it will respond to certain forms of treatment.



Phases of CML

The phase of CML is mainly based on the number of blasts (immature white blood cells) in your blood and bone marrow. Knowing the phase of your disease helps doctors plan your treatment. It also helps them predict how the disease will progress.

CML is divided into three phases:



Chronic phase

- Most people are diagnosed at this phase
- You may or may not have symptoms
- You may have more white blood cells than usual
- Treatment is often successful
- Without treatment, CML will progress to the next phase

Accelerated phase

- The number of CML cells increases more quickly
- Symptoms appear, including fatigue, fever, weight loss, and enlarged spleen
- Without treatment, accelerated CML will progress to the blast phase

Blast phase

- Blast cells may have spread outside the blood and/or bone marrow to other parts of the body
- CML cells show new, abnormal changes



CML treatment

Treatment for CML has improved significantly over the past 20 years. Many people with CML go into remission. Remission occurs when the number of CML cells is controlled so that it reaches a low, nearly undetectable level. Today's drug therapies can offer many people living with chronic phase CML a good quality of life and a normal lifespan.

You may experience mild to severe side effects during treatment, depending on your age, overall health, and treatment plan. Speak to your doctor if you are experiencing side effects. Side effects can affect people in different ways. Most disappear once treatment ends. New drugs and therapies can help control most side effects.

Types of treatment

Common CML treatments include:

Tyrosine kinase inhibitors (TKIs)

are a type of targeted therapy taken in pill form. They are the preferred treatment for almost all newly diagnosed cases of CML, as they are an effective CML treatment and usually well tolerated.

- **Potential side effects:** nausea, vomiting, diarrhea, rashes, muscle cramps, bone pain, fatigue, headaches, fluid retention, lower blood cell counts, and a low risk for heart attack and stroke

Lowering high white blood cell counts (leukapheresis)

uses a machine similar to dialysis to remove white blood cells from your blood.

- **Potential side effects:** low calcium, low red blood cells, and low platelet count

Chemotherapy

uses medicine to kill cancer cells. It is often given in combination with immunotherapy.

- **Potential side effects:** nausea, diarrhea, vomiting, loss of appetite, problems concentrating (known as brain fog), fatigue, shortness of breath, temporary hair loss, mouth sores, rashes, and neuropathy (nerve damage)

Immunotherapy

uses an intravenous drug that can either boost or pause your immune system to help your body fight cancer. Immunotherapy is done in addition to chemotherapy.

- **Potential side effects:** rashes, fatigue, diarrhea, nausea, vomiting, and decreased thyroid hormone levels

A stem cell transplant

transfers a healthy person's stem cells to your body to slow the cancer's growth.

- **Potential side effects:** low blood cell counts (white, red, and platelets), infection, bleeding, anemia, graft-versus-host disease (GvHD), veno-occlusive disease (small vessels leading to the liver are blocked), as well as issues with your digestive system, skin and hair, pain, kidney, lung, heart, eyes, or central nervous system

Clinical trials are research studies that aim to improve the care and treatment of people living with cancer.

For some people with a blood cancer, a clinical trial may be the best treatment choice. Talk to your healthcare team for more information.

Factors that affect treatment

Discuss your treatment options with your doctor to make sure you understand the benefits and risks of each approach. Your treatment plan is based on:

- Your age and overall health
- Size of your spleen
- Phase of your CML
- Your prognostic score (whether you are low/intermediate risk or high risk)
- Your platelet counts
- Your blast count (concentration of immature white blood cells)
- Concentration of white cells in your blood

Long-term or late effects of treatment

Medical follow-up is important during and after treatment for CML. You may need blood tests with or without repeat bone marrow tests to determine if you need further treatment. Your medical team will provide a care plan listing follow-up visits and the tests you will have at those visits.

- **Long-term side effects** are common and can last for months or years after treatment ends. Examples include chronic fatigue, brain fog, and increased risk of infection.
- **Late effects** are medical problems that do not show up until years after treatment ends. See your doctor to get follow-up care for possible early detection of heart disease, secondary cancers, fertility issues, thyroid problems, trouble concentrating, and chronic fatigue.



Living with CML can be overwhelming. Seek medical help if you feel “down” or “blue” or don’t want to do anything and your mood does not improve over time. These could be signs of depression, an illness that should be treated even when you are undergoing treatment for CML. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.

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