

Track your side effects with the LLS Health Manager App
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Managing your side effects is an important part of cancer care. Tracking your medication, side effects, and food and nutrition intake allows you to share the information easily with your doctor to identify patterns and strategies.

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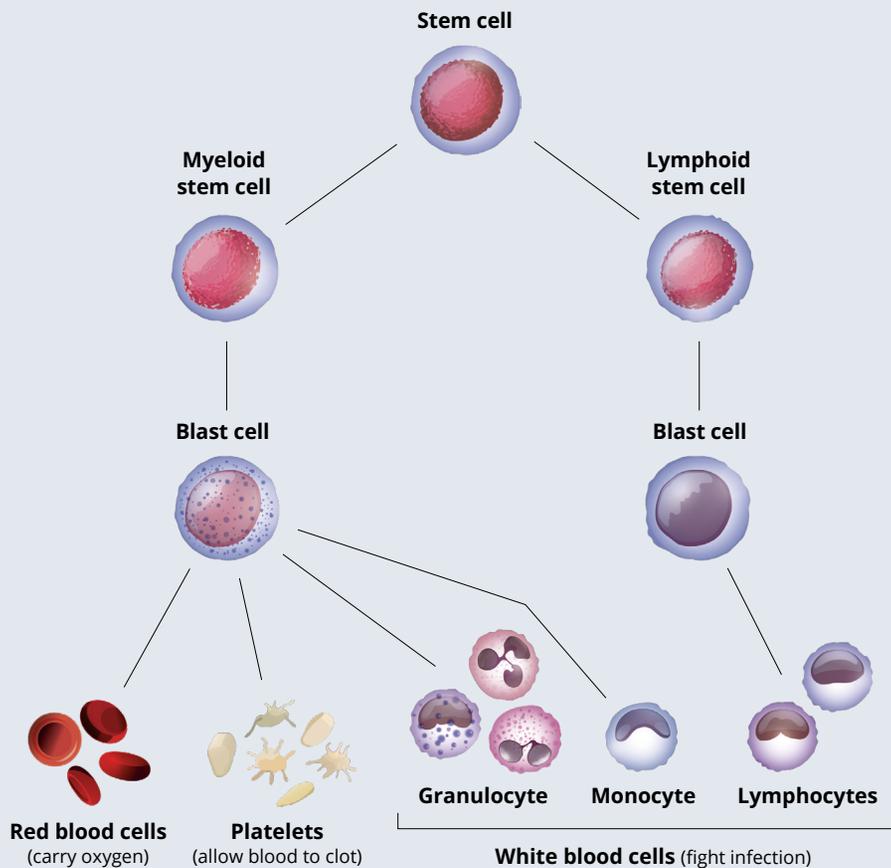
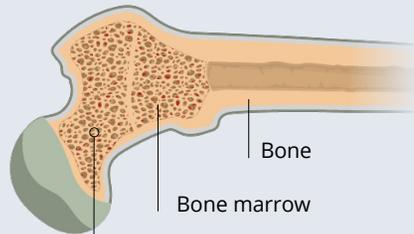
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Understanding and Managing Chronic Myeloid Leukemia
CML

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



What is this booklet for?

You or your loved one has been diagnosed with chronic myeloid leukemia (CML). This booklet was designed to answer some questions you may have about chronic myeloid leukemia (CML). It summarizes what CML is and its phases, as well as treatment options available in Canada and their side effects.

This booklet can also serve as a starting point for treatment discussions with your doctor, so that you can decide together what is best for you based on various factors such as the CML phase, your health and age, as well as your personal preferences and lifestyle.

Once you have a better understanding of treatment options, you can stay informed and take an active role in your CML treatment process.

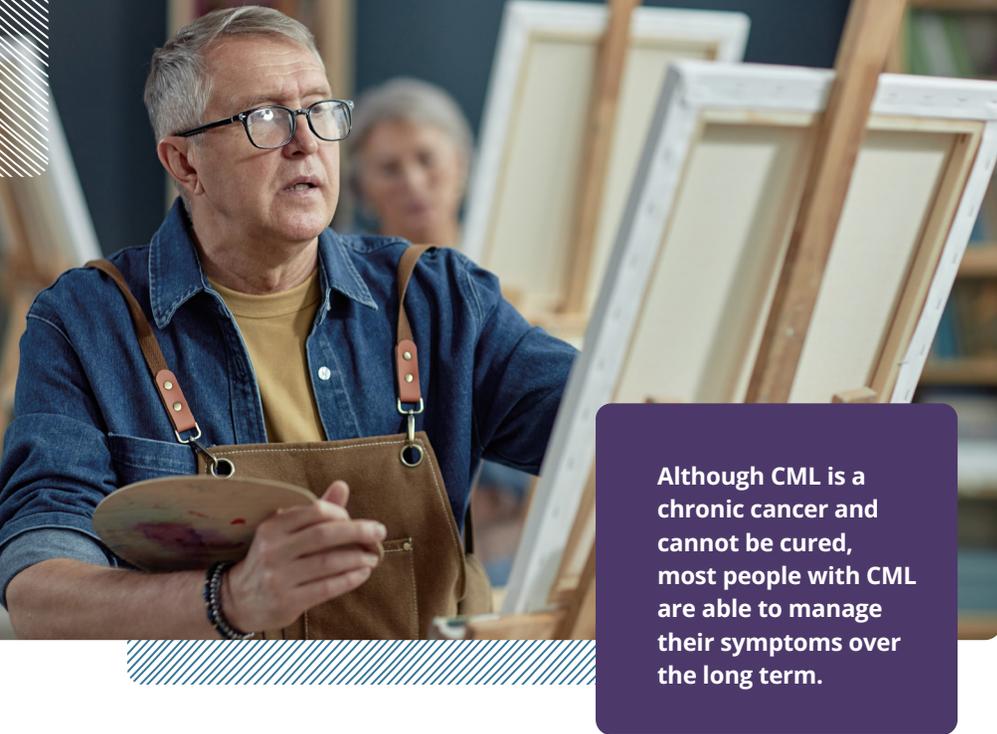
Development of blood cells

CML starts in abnormal myeloid stem cells and develops slowly. Myeloid stem cells normally develop into red blood cells, granulocytes, monocytes or platelets.

- Red blood cells carry oxygen to all tissues of your body.
- Granulocytes and monocytes are types of white blood cells that destroy bacteria and help fight infection.
- Platelets form clots in blood to stop bleeding.

Usually in CML, there are too many granulocytes.

Normally, as these stem cells develop, they go on to become immature blood cells known as blast cells.



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

What is CML?

Chronic myeloid leukemia (CML) is the third most common type of leukemia diagnosed in adults in Canada.

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

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:

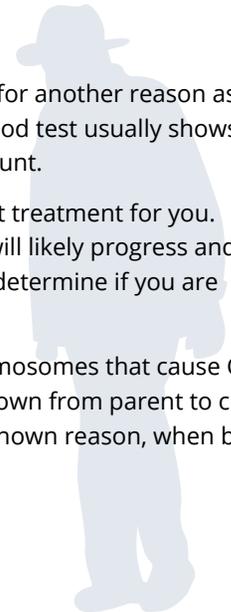
- Weakness, tiredness, and feeling out of breath during normal activity
 - When your red blood cell count is low (anemia)
- Fevers and night sweats
 - Possibly a response from your immune system
- Bone pain
 - When your white blood cells accumulate, causing your bone marrow to expand
- Weight loss
 - 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

CML is often discovered when you have a blood test for another reason as there may be no obvious signs or symptoms. The blood test usually shows that you have an abnormally high white blood cell count.

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, accelerated, and blast (or blast crisis) phases.

Phase	What is it?	Treatment Goals
Chronic	Most people diagnosed at this phase. May or may not have symptoms. More white blood cells than usual. Without treatment, CML will progress to accelerated phase.	To keep the CML cells that contain the BCR-ABL1 gene at a very low level. To return blood cell counts (red blood cells, white blood cells, and platelets) to normal levels.
Accelerated	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.	To kill all cells that contain the BCR-ABL1 gene. If this is not possible, the goal is to return the disease back to the chronic phase.
Blast, or blast crisis	Blast cells may have spread outside the blood and/or bone marrow to other parts of the body. CML cells show new, abnormal changes.	To return the disease to the chronic phase

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.

Your healthcare team will suggest treatment based on your needs, and work with you to develop a treatment plan. Don't hesitate to share your personal preferences and lifestyle with your healthcare providers and take the time to ask any questions you have.

The first treatment your doctor gives you is known as "first line" treatment. For some people with CML, first-line treatment may not work because of side effects or drug resistance (when the cancer does not respond to treatment). In that case, your doctor would give you a different type of treatment, referred to as "second line" treatment. At every step, your healthcare team will check your blood and bone marrow to closely monitor your response to treatment.

Not everyone with CML receives the same treatment. Various factors will help your doctor determine the treatment that is most appropriate for you.

Factors that affect treatment options

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
- Your 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

You may experience mild to severe side effects during treatment, depending on your age, overall health, and other factors. 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.

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.

Types of treatment and their side effects

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 (VOD), as well as issues with your digestive system, skin and hair, pain, kidney, lung, heart, eyes, or central nervous system

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.

What other questions can you ask your doctor or other members of your healthcare team?

Consider bringing this list of questions to your next doctor’s appointment.

Diagnosis

What tests do you recommend for me?

Where will the tests take place? How long will the tests take?

How do I prepare for testing? How will the test be done? What can I expect?

What is the exact diagnosis? What phase is the disease?

General treatment

What is the goal of my treatment?

What are all of my treatment options?

What are the benefits and risks of each of these treatment options?

Should I start treatment now? Why or why not?

What should I do to be ready for treatment?

Which one do you recommend for me? Why?

What is the treatment frequency?

How long will treatment last?

Will treatment require a hospital stay or will it be an outpatient treatment?

What kind of testing will be done to monitor the disease and its treatment?

How often will the testing be needed?

What should be avoided or taken with caution while receiving treatment?

Am I eligible to participate in a clinical trial?