



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

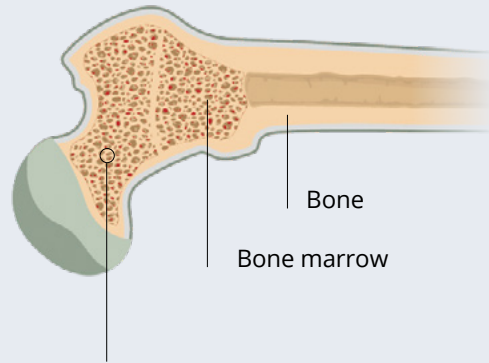
Understand
what happens
next

What is leukemia?

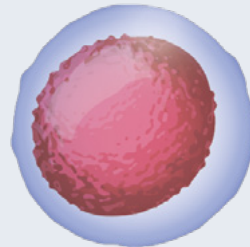
Leukemia is a cancer that affects the blood and bone marrow. Blood cells form in the bone marrow, which is the soft, spongy material inside bones.

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

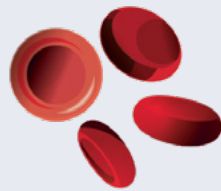
Blood is created in the **bone marrow** (the spongy part inside the bone).



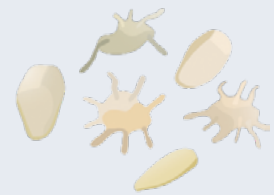
Stem cell



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)

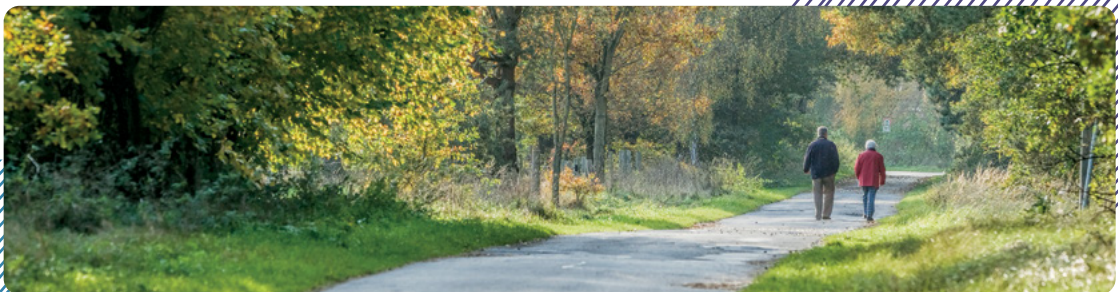
About CML

- Rare type of leukemia
- Can happen when cells that make the blood develop a genetic change called BCR-ABL1 (Philadelphia chromosome), and the bone marrow makes too many white blood cells
- Not passed down from parent to child
- Usually affects older adults (65 and older) and is more common in men

Signs and symptoms

CML develops slowly. There may be no obvious signs or symptoms. CML is often discovered when you have a blood test for another other reason. The blood test shows that you have an abnormally high white blood cell count. This large number of white blood cells crowds out other blood cells.

- Weakness, tiredness, and feeling out of breath during normal activity
 - When you have low red blood cell counts
- 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



After your diagnosis

With your diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how your CML will likely progress and how you may respond to treatment.

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 your blood if you have leukemia.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual with your chromosomes. They are usually done at the same time.
Cytogenetic analysis	This test looks for changes in chromosomes to help confirm CML.
FISH (<i>fluorescence in situ hybridization</i>)	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 your 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 your disease is based mostly 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 your 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
- People often have more white blood cells than is usual
- Treatment is often successful
- Without treatment, CML will progress to one of the next two phases

Accelerated phase

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

Blast phase (also called blast crisis 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 of CML has improved significantly over the past 20 years. Many people with CML go into remission, which happens when the number of CML cells is controlled to 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.

Types of treatment

Each phase of CML has a different type of treatment. Your doctor will determine the best course of treatment for you based on the phase, your test results, and these factors:

- Age
- Size of the spleen
- Platelet counts
- Blast count (concentration of immature blood cells in your blood)
- Concentration of white cells in your blood



Chronic phase treatment

The goal of treatment in the chronic phase is to keep the CML cells that contain the BCR-ABL1 gene to a very low level. **Tyrosine kinase inhibitor (TKI) therapy** is the standard treatment used for the chronic phase CML. TKIs are taken in pill form. Many people are able to manage their CML for long periods of time with TKIs. There are several versions of TKIs, so if one kind does not work or is difficult to tolerate, other types are available. Other treatment options are reserved for uncommon circumstances when TKIs cannot be given or do not work – these options include **interferon alpha** or **chemotherapy**, which slow down the production of leukemia cells.

Accelerated phase treatment

At this stage, the goal of treatment is to get CML back to the chronic phase. Standard treatments don't work as well in the accelerated phase. This is because the cancer cells start to change in new ways, and it's important to bring down your white blood cell counts.

If you are in the accelerated phase when you are diagnosed with CML, the first treatment option is TKIs. If you move from chronic to accelerated CML while taking TKIs, your doctor may give you a higher dose or a different medication. Since the chance of controlling CML longterm is lower in accelerated phase than in chronic phase, your physician may discuss the possibility of an **allogeneic bone marrow transplantation (BMT)** with you. BMT is a procedure to replace damaged or destroyed bone marrow with healthy bone marrow cells from a donor.

Blast phase treatment

Blast phase CML is more difficult to treat because the leukemia cells have become very abnormal, like more severe forms of leukemia. People with blast phase CML may receive TKI therapy and chemotherapy. Since the chance of controlling CML longterm is lower in blast phase than in accelerated or chronic phase, your doctor may discuss the possibility of an **allogeneic BMT** with you.

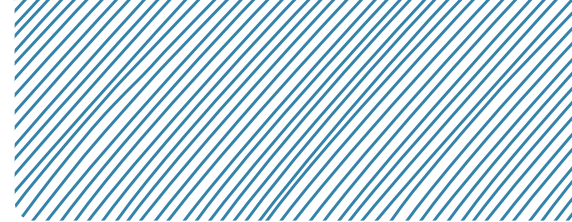


Remission without further treatment

New treatments for CML mean that you may go into remission and show no signs of the disease for a long time. If your CML has been under control for several years, you may even be able to stop taking medication for CML. This is an option that you can discuss with your doctor.

Children and young adults with CML

A small number of people with CML are children and young adults. There is no standard treatment for children with CML, so children should be seen by doctors who specialize in treating pediatric blood cancer.



Treatment side effects

When you begin CML treatment, you may experience mild to severe side effects, depending on your age, overall health, and treatment plan. Most side effects decrease once your body adjusts to treatment or when your treatment ends. New drugs and therapies can help control side effects, such as nausea and vomiting. Speak to your doctor if you are experiencing side effects.

TKI therapy side effects

The most common side effects of TKI therapy are:

- Nausea and vomiting
- Diarrhea
- Rashes
- Fatigue
- Headaches
- Fluid retention
- Lower blood cell counts

TKIs can have serious interactions with other prescription medications, over-the-counter medications, supplements, and certain foods. Be sure to talk to your doctor about your medications, vitamins, and diet. It is important to have regular blood tests to monitor the response and side effects while on TKI.

Treatment with interferon may be associated with flu-like symptoms, such as fatigue, fever, and muscle pains. It can also be associated with changes in mood or depression.

Other side effects

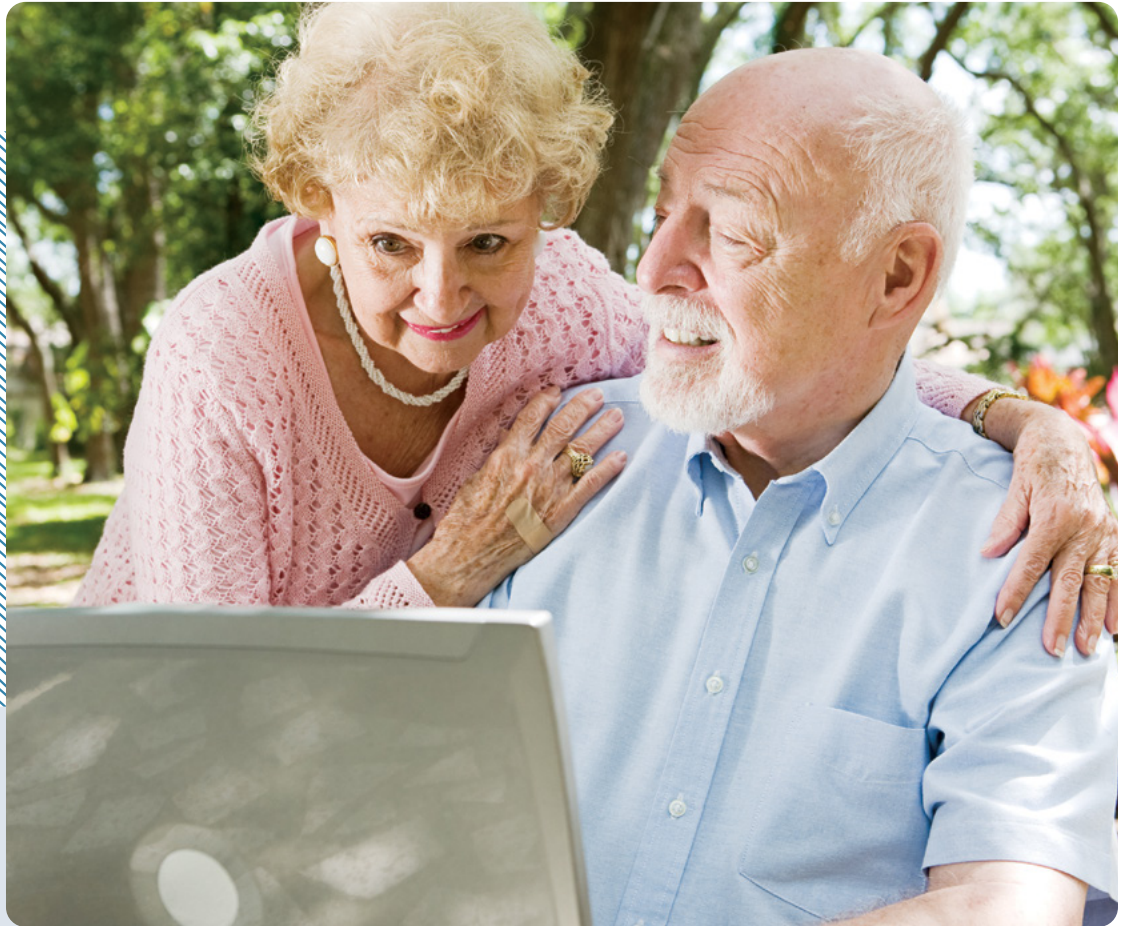
If you undergo other forms of treatment, including chemotherapy, you may experience these side effects:

- Nausea and vomiting
- Diarrhea
- Temporary hair loss
- Mouth sores and rashes
- Neuropathy, which is nerve damage from treatment that can make your fingers and toes feel numb or tingle

Long-term or late effects of treatment

Medical follow-up is important during and after treatment for CML. You may need blood tests, bone marrow tests, or molecular tests to determine if you need adjustments to your treatment plan. Your medical team should provide you with a care plan listing the frequency of 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. One example is fatigue.
- **Late effects** are medical problems that do not show up until years after treatment. 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 hard. 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’re undergoing treatment for CML. Treatment for depression has important benefits for people living with cancer.

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