



## WHAT YOU NEED TO KNOW

Chronic neutrophilic leukemia (CNL) is a type of leukemia. What does it mean and how will it affect you?

This fact sheet will help you:

Learn about CNL and how it is diagnosed

Get an overview of treatment options

**Understand what** happens next

## What is leukemia?



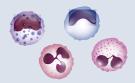
Leukemia is a cancer of the blood and bone marrow. Bone marrow is the soft, spongy material inside bones. Blood cells are formed in the bone marrow. There are three kinds of blood cells:



Red blood cells (carry oxygen)



(allow blood to clot)



White blood cells (fight infection)

When you have leukemia, cancerous blood cells form and push out healthy blood cells.

#### **About CNL**

- Belongs to a group of blood cancers where the bone marrow makes too many neutrophils, a type of white blood cell
- Affects people of all ages
- · Affects both men and women
- Can develop slowly or progress quickly
- Can change to a more aggressive type of leukemia called acute myeloid leukemia

### Signs and symptoms

Most people with CNL have no obvious signs or symptoms, and the disease is uncovered during a routine doctor's visit. The signs and symptoms can be similar to other less serious diseases. You may experience:

- Fatigue or tiredness that does not improve with rest
- When your red blood cell count is low (anemia) or your body is using more energy
- Weight loss
  - When you are eating less or using more energy
- Bruising easily
  - When your body is not producing enough platelets for your blood to properly clot
- Bone pain
  - When your white blood cells accumulate, causing your bone marrow to expand
- Night sweats
  - Possibly a response from your immune system
- Pain or a full feeling below the ribs on the left side
  - When your spleen or liver becomes enlarged, causing your abdomen to swell

CNL is a very rare type of leukemia. To date, only about 200 cases have been reported worldwide.

## After your diagnosis

With your diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how CNL 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 your blood. A very high neutrophil count is a key feature of CNL.
Comprehensive metabolic panel	This group of blood tests, or blood chemistry profile, measures the levels of certain substances released into your blood. CNL patients often have high levels of specific enzymes and vitamin $B_{12}$ .
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells to see if anything unusual is happening with your chromosomes. The tests are usually done at the same time. The results can show higher neutrophil counts if you have CNL.
Molecular testing	This genetic test looks for a specific mutation in your genes. Most people with CNL carry a gene mutation called CSF3R.

### **CNL** treatment

CNL is very rare, so there is no standard treatment. Your treatment will focus on managing the symptoms, blood counts and complications rather than curing the disease. Long-lasting remission is not likely with CNL, especially if your disease progresses to acute myeloid leukemia. (Remission happens when there is no evidence of leukemia in a person's body.) New treatments may be available through clinical trials.

## Types of 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, overall health status, and prognosis (the likely outcome of the disease).

### Drug therapy

is the main form of treatment, including chemotherapy in pill form.

- **Hydroxyurea** is the most common drug used to treat CNL. It is effective in controlling high white blood cell counts and treating an enlarged spleen.
- Interferon alpha has had some success as a drug treatment. It is also used to treat a more progressive form of CNL.
- **Ruxolitinib** is a kinase inhibitor (a drug that blocks certain enzymes). Health Canada has approved it to treat other forms of cancer. It is being studied in a clinical trial for treating CNL.

### Allogeneic stem cell transplant

transfers a healthy person's (donor) stem cells to your body following chemotherapy treatment to slow the growth of the disease. This can be a high-risk procedure. For some people with CNL, it may be the only potential option to try to cure the disease. You should discuss with your doctor if this treatment is applicable in your case.

#### **Treatment side effects**

When you begin your treatment for CNL, you may experience mild to severe side effects. Most side effects disappear once your treatment ends. New drugs and therapies can help control most side effects. Speak to your doctor if you are having side effects.

#### Common side effects

You may experience side effects such as:

- Mouth ulcers (open sores), changes in your sense of taste, and skin ulcers or a rash from hydroxyurea treatments
- · Moderate to severe flu-like symptoms, confusion, and depression from interferon alfa treatments
- Possibility of complications from infections from ruxolitinib treatment, as it lowers blood cell counts

# Long-term of treatment

Medical follow-up is important after treatment for CNL. You may need blood or late effects tests, bone marrow tests, or molecular tests to determine if you need further treatment. 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 ends. Examples include chronic fatigue and problems concentrating (known as chemo brain).
- 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 and secondary cancers.



Living with CNL 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're undergoing treatment for CNL. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.

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Never hesitate to contact us, we're here to help!

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