ABOUT BLOOD CANCERS

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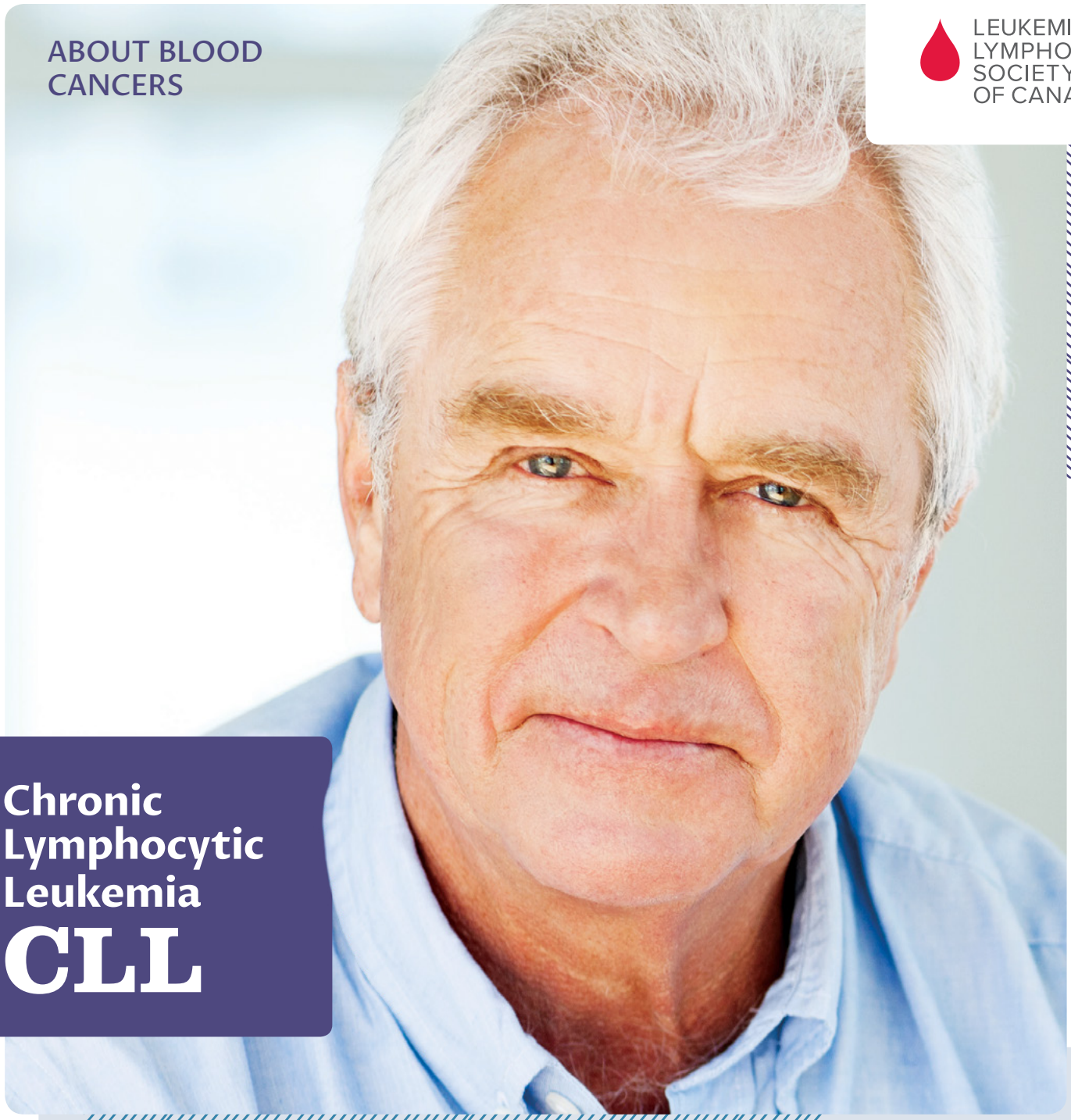


Chronic Lymphocytic Leukemia
CLL

WHAT YOU NEED TO KNOW

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

This fact sheet will help you:

- Learn about CLL and how it is diagnosed
- Get an overview of treatment options
- Understand what happens next

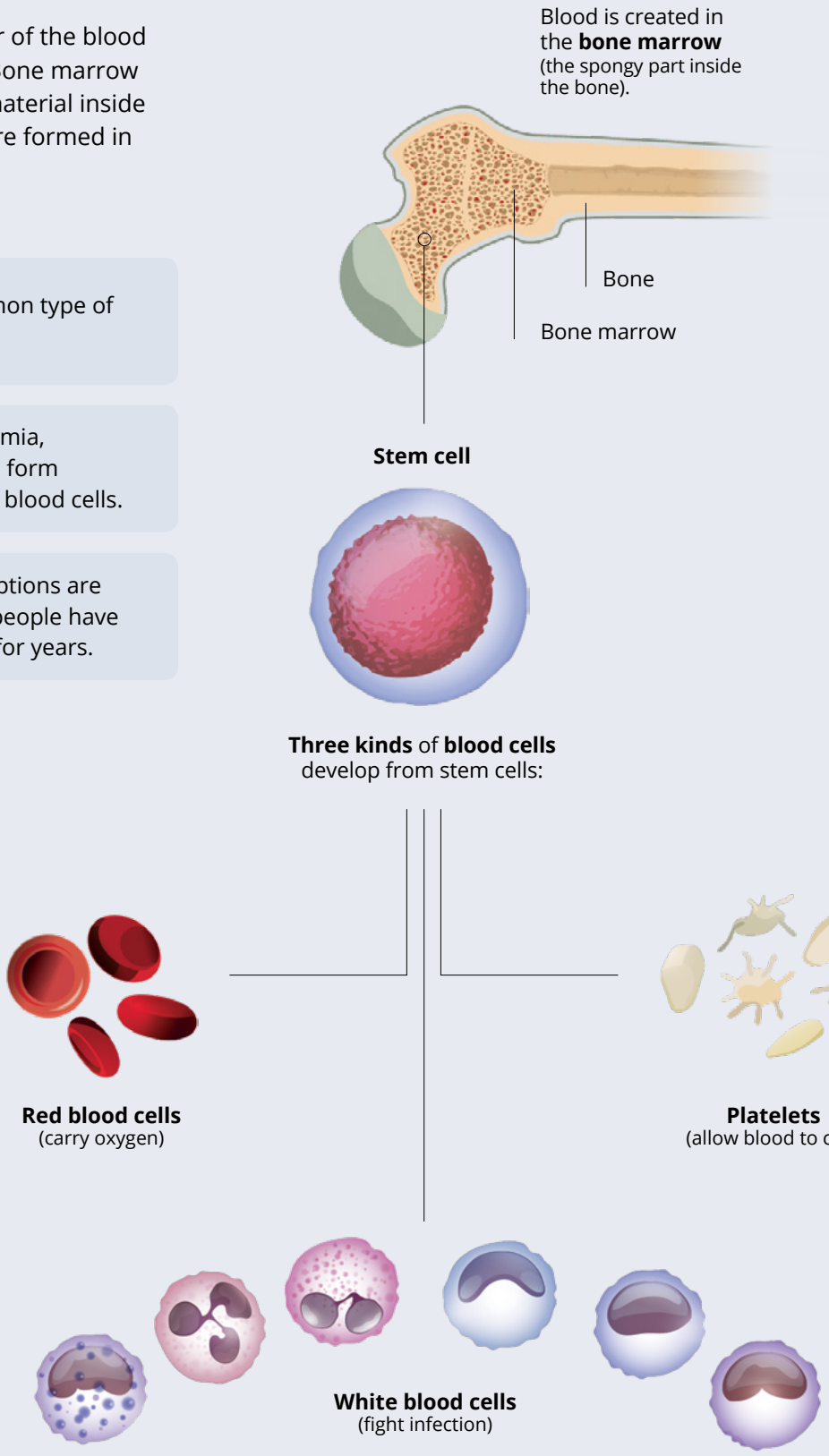
What is leukemia?

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.

CLL is the most common type of leukemia in adults.

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

Effective treatment options are available, and many people have a good quality of life for years.



About CLL

- One of four main types of leukemia
- Involves mature lymphocytes (a type of white blood cell) in the blood, bone marrow, lymph nodes, or spleen
- B lymphocytes (type of white blood cell that fights infections) lose the ability to function normally
- Normal red cells and platelets are crowded out and the number of healthy blood cells is usually lower than normal
- Can be stable for many years or grow quickly
- No obvious reason for developing CLL and no way to prevent it

Signs and symptoms

In some people with CLL, there are no obvious signs or symptoms, and the disease is uncovered during a doctor's visit and a routine blood test. The symptoms often develop slowly. Many people have little or no change in their health for years.

You may experience:

- Fatigue, shortness of breath during normal physical activities, and a pale complexion
  - When your red blood cell count is low (anemia)
- Weight loss
  - When you are eating less or using more energy
- Bruising easily and ongoing bleeding from minor cuts
  - When your platelet count is low (thrombocytopenia)
- Infection
  - When your immune system is not working properly
- Swollen lymph nodes and spleen
  - When your CLL cells accumulate

Signs and symptoms of other cancers

With CLL, you have a higher risk of other cancers, especially skin cancers. Your immune system may not be able to recognize or remove abnormal cells. It's important to continue to do cancer screening and skin checks. Your doctor will work to determine the cause of the symptoms through physical exams and blood tests.

After your diagnosis

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

Name of test	Description
Medical history and physical exam	The doctor reviews past illnesses, injuries, and symptoms. They examine your lungs, heart, and other organs.
Complete blood count	This test measures the number of red blood cells, white blood cells, and platelets in a sample of your blood to find out if the counts are high or low. With CLL, you will often have a high number of lymphocytes (a type of white blood cell) and low red blood cell and platelet counts.
Flow cytometry	During this test, cells are taken from your blood or tissue biopsy to detect which proteins or markers (antigens) you have. This helps to determine if you have CLL.
Immunoglobulin test	This lab test measures the number of immunoglobulins you have. These proteins help your body fight infection. With CLL, you may have low levels of immunoglobulins.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual in your chromosomes. They are usually done at the same time. The results can be a marker to allow the doctor to see any changes after treatment begins.
Fluorescence *in situ* hybridization (FISH)	This lab test looks at genes and chromosomes in cells to detect changes to the chromosomes of CLL cells.
Gene sequencing	This test checks if you have specific changes to your genes. This helps to determine your treatment plan.

Stages of CLL

Identifying the stage of your disease is an important step to planning your treatment. The stage of CLL refers to how your disease has progressed. **It does not determine how well you will respond to treatment.**

Staging systems consider certain factors, including:

- How high your blood and marrow leukemic lymphocyte counts are
- Size and distribution of your lymph nodes
- Size of your spleen
- How much your blood platelet counts have decreased
- Type anemia affecting you

With CLL, doctors use one of two staging systems: the Rai staging system or the Binet staging system:

Rai staging system

The Rai staging system classifies CLL into the following five stages based on factors at the time of diagnosis. All five stages involve an abnormal increase in the number of lymphocytes in the blood and marrow (also referred to as lymphocytosis).

Low risk 0	is marked by this abnormal increase only.
Intermediate risk I	also involves enlarged (swollen) lymph nodes.
Intermediate risk II	also involves swollen lymph nodes, liver, or spleen.
High risk III	also involves anemia (low red blood cell count).
High risk IV	also involves low platelet count.

CLL treatment

CLL treatment can vary greatly. Your treatment will focus on slowing the growth of CLL cells and will help you go into remission (where there is no evidence of leukemia in your body). Treatment will also help to manage the symptoms and complications of CLL, including infections and fatigue.

The slower-growing form	may not need immediate treatment and can remain stable for years. There will be more lymphocytes and a normal or slightly lower level of red cells, platelets, and neutrophils (a type of white cell) in your blood.
The faster-growing form	may need treatment sooner, as the high number of CLL cells blocks normal cell production. This gives you a lower red blood cell and platelet count.

Types of treatment

Watch and wait or active surveillance	delays treatment until it is possible that the disease will progress. This approach is for people with slow-growing CLL and no symptoms.
Chemotherapy	uses medicine (chemicals) to kill cancer cells. A combination chemotherapy procedure uses two or more chemotherapy drugs.
Targeted therapies	include a type of drug therapy to target specific substances on the cancer cell. The drug is often given in pill form and is more commonly used for high-risk people.
Monoclonal antibody therapies	are lab-made antibodies. They are used to attach specific markers on the surface of CLL cells to destroy them. These therapies are often given in combination with other treatment options.
Radiation therapy	uses x-rays or other high-energy rays that can kill CLL cells.
Immunotherapy	boosts or pauses your immune system to help your body fight cancer. Immunotherapy is done in addition to chemotherapy.
Splenectomy	is a surgical procedure to remove your spleen, an organ located in the upper part of your abdomen. This surgery is used to help with discomfort and to improve blood cell counts.
Supportive care	is used to prevent or treat CLL symptoms and therapy side effects. Common methods include antibiotics and blood cell growth factors (these help to grow red and white blood cells and platelets).

Clinical trials are research studies run by doctors to improve the care and treatment of people living with cancer. For some people with CLL, 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 status
- Physical exam and lab test results
- The stage of CLL and your risk category
- The molecular profile of your CLL (a genetic test is used to determine the best treatment option for your cancer)

Treatment side effects

When you begin your treatment for CLL, you may experience mild to severe side effects, depending on your age, your overall health, and your treatment plan. Side effects can vary in duration and severity and affect people in different ways. 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: • Aches, diarrhea, and constipation from chemotherapy and radiation • Fatigue, infections, and low blood pressure from chemotherapy • Low counts of platelets, red blood cells, and white blood cells from chemotherapy • Mouth sores, upset stomach, and vomiting from chemotherapy and radiation
Long-term or late effects of treatment	Medical follow-up is important after treatment for CLL. You may need blood 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 how often you will need 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. An example is chronic fatigue. • **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 problems, thyroid problems, problems concentrating, and chronic fatigue.

Living with CLL can be overwhelming. Seek medical help if you are feeling "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 CLL. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.

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