ABOUT BLOOD CANCERS

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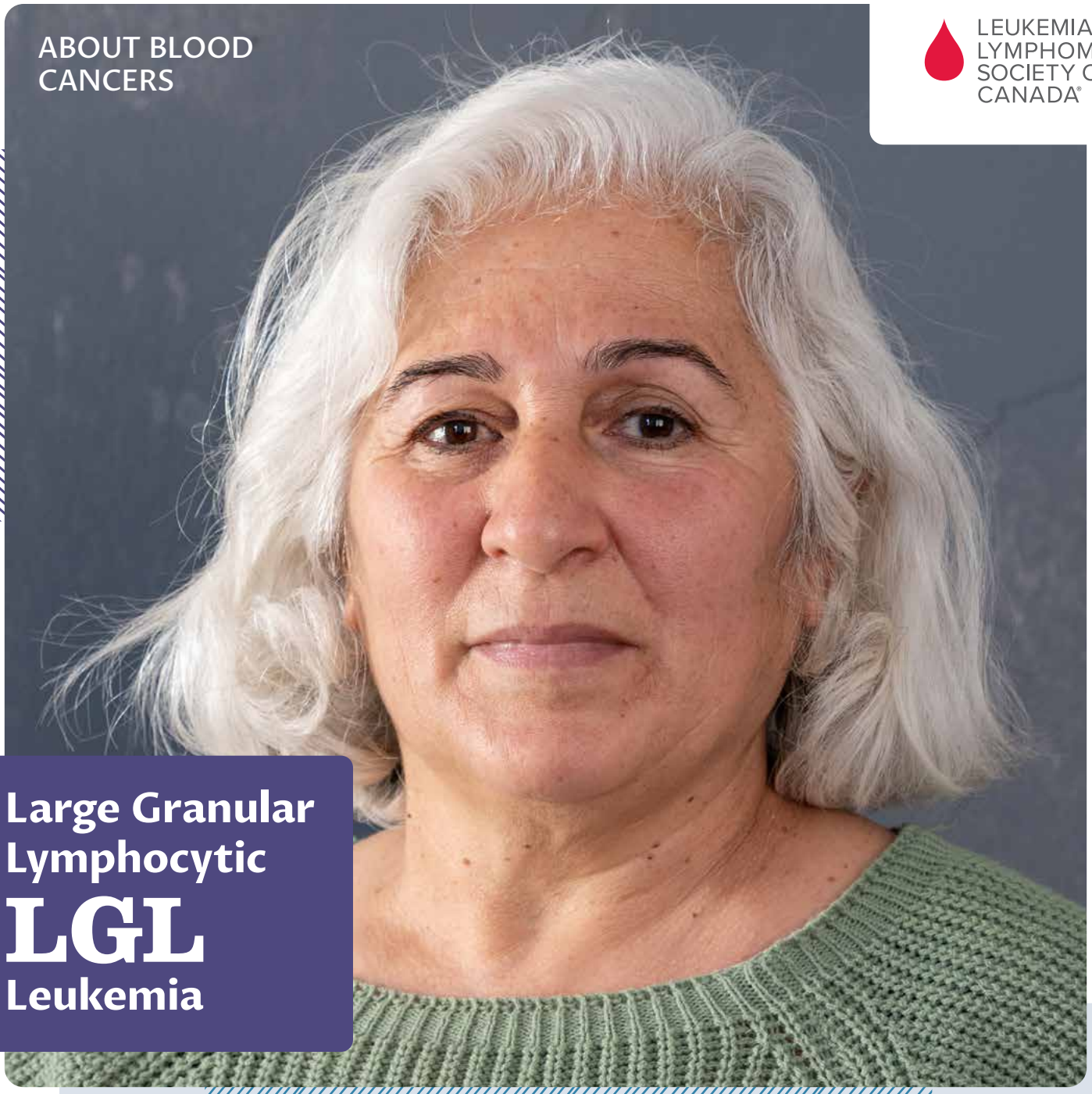


Large Granular Lymphocytic LGL Leukemia

WHAT YOU NEED TO KNOW

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

This fact sheet will help you:

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

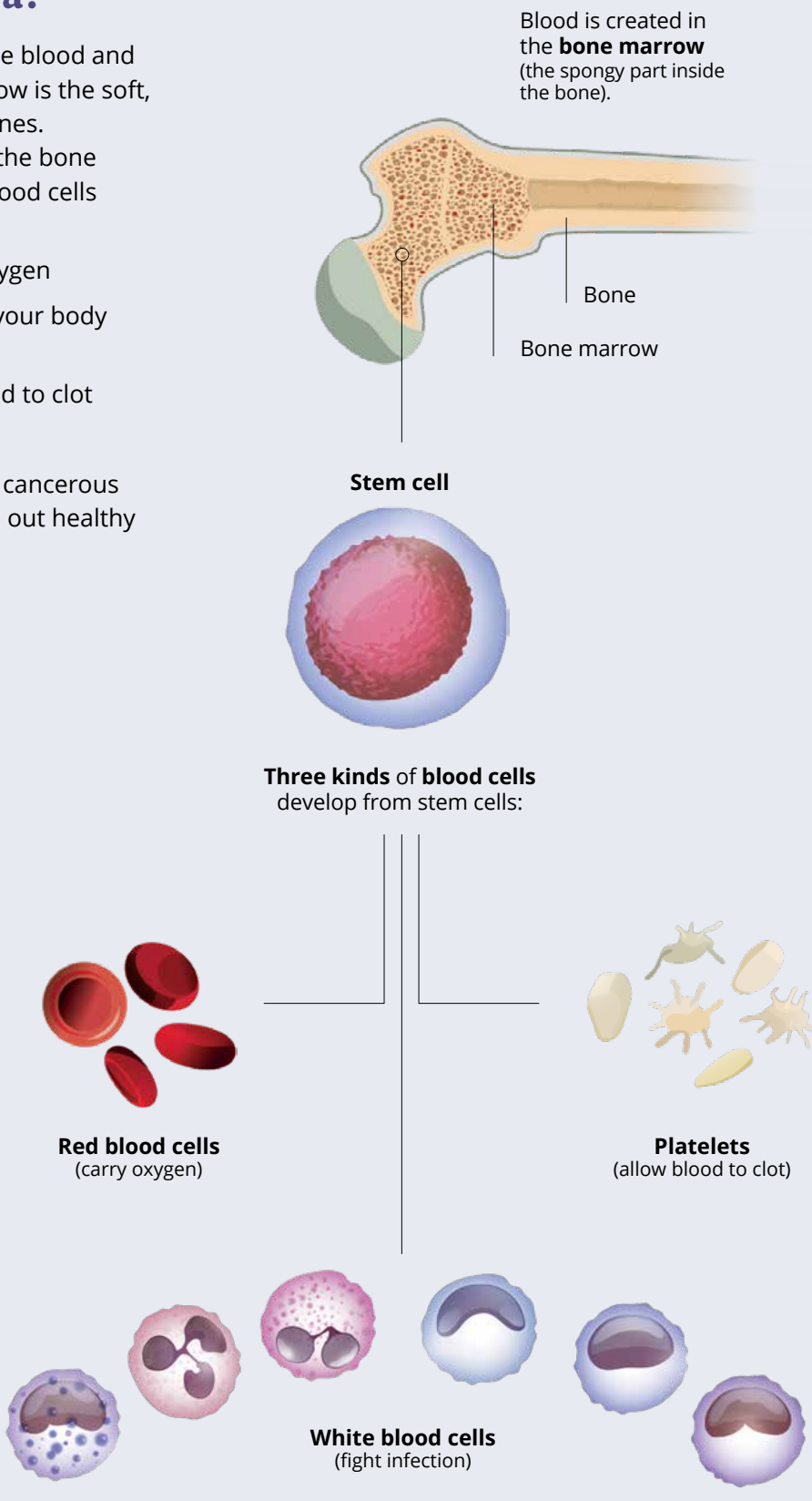
What is leukemia?

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** help your body fight infection
- **Platelets** help your blood to clot (stop bleeding)

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

Leukemia is a cancer of the blood and bone marrow.



About LGL leukemia

- LGL leukemia affects a specific type of white blood cell known as a lymphocyte (part of the body's immune system that helps fight infection)
- This type of leukemia affects larger lymphocytes, with granules (small grains) that are visible
- It can develop slowly (chronic) or progress quickly (aggressive)
- It affects both men and women
- The average age of diagnosis is 60 years (only 1 out of 4 people with LGL leukemia are younger than 50 years)

There are two types of LGL leukemia. Each type may be chronic or aggressive:

- **T-cell LGL (T-LGL):** This type starts in your T cells. T cells fight infection, destroy abnormal cells, and control your immune response. T- LGL is often slow growing.
- **Natural killer cell LGL (NK-LGL):** Large natural killer (NK) cells are found in the blood. These cells attack abnormal or foreign cells. NK-LGL is often slow growing.

Chronic T-cell and NK-cell LGL leukemia

Risk factors

Certain factors can increase your risk for chronic T-cell and NK-cell LGL leukemia. For example, the risk is higher if you have an autoimmune disease (where your body attacks healthy cells by mistake), such as rheumatoid arthritis.

Signs and symptoms

Most people with chronic T-cell and NK-cell LGL leukemia have symptoms at diagnosis. Changes in your blood cell counts are common. You may also experience:

- Bacterial infection most commonly affecting skin, mouth, throat, and around the rectum
  - When your white blood cell count is low (neutropenia)
- Fatigue and weakness
  - When your red blood cell count is low (anemia)
- Weight loss
  - When you are eating less or using more energy
- Fever
  - From the cancer cells
- Night sweats
  - Possibly a response from your immune system
- Pain or full feeling below the ribs on the left side
  - When you have an enlarged spleen (splenomegaly)
- Bleeding
  - When your platelet count is low (thrombocytopenia)

Your diagnosis

With a diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how chronic LGL leukemia will likely progress and how you may respond to treatment. Here are some possible tests you may do:

Name of test	Description
Medical history and physical exam	The doctor will review past illnesses, injuries, and symptoms, examining 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 LGL leukemia, your lymphocyte count may be normal or low.
Blood cell examination	This test looks at blood cells under a microscope to see if they appear normal. With LGL leukemia, you may have a large number of abnormal cells.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual in your chromosomes (for example, cancer cells). They are usually done at the same time.
Flow cytometry	During this test, cells are taken from your blood or tissue biopsy to detect proteins or markers (antigens). This test helps to determine if the LGL leukemia cells are T cells or NK cells.
Polymerase chain reaction (PCR)	This test detects residual (leftover) LGL cells whose concentration is too low to be seen with a microscope.

LGL leukemia treatment

Treatment for T-cell and NK-cell LGL chronic leukemia involves a similar approach and varies between people. Your treatment will focus on **remission** (eliminating LGL leukemia cells in your blood and bone marrow) and getting your blood counts back to normal. Treatment will also help to manage the symptoms and complications of LGL leukemia.

Types of treatment

- **Active surveillance (watch and wait)** means waiting for the disease to progress before starting treatment. Most people will eventually need treatment.
- **Immunosuppressive therapy** lowers your body's immune system to fight infections.
- **Drug therapies** include alkylating agents (drugs that react with DNA to prevent cell growth) and purine analogs (drugs that kill cancer cells).
- **Splenectomy** is a surgical procedure to remove your spleen, an organ located in the upper part of your abdomen.

Some people don't respond to treatment and will be treated with different drugs. Others respond at first, but eventually, their LGL leukemia returns, and they need more treatment. Clinical trials may be an option. Talk to your healthcare team.

People whose disease has **relapsed** (returned) may try the initial treatment again or another immunosuppressive treatment. People whose disease is **refractory** (has not responded to treatment) may be treated with purine analogs, drug therapy, or a splenectomy (this surgery has shown limited results).

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.

Aggressive T-cell and NK-cell LGL leukemia

People with an aggressive form of this type of leukemia may have an enlarged liver and spleen, fever, weight loss, and night sweats. Unfortunately, aggressive T-cell and NK-cell LGL leukemia does not respond to treatment. Often, this leukemia is treated with:

- **Induction chemotherapy,** which is intensive chemotherapy to kill cancer cells to control LGL leukemia. This includes chemotherapy in the spinal space to ensure there is no leukemia.
- **Consolidation therapy,** which is treatment given when your cancer has disappeared after the initial therapy).
- **Stem cell transplant** at the time of first remission.
- **Participation in a clinical trial.**

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
- Your medical history
- Whether the leukemia involves your T cells or your NK cells
- Your lab test results
- Whether you have a chronic or aggressive form of leukemia
- Your preference

Treatment side effects

When you begin your treatment for LGL leukemia, you may already have abnormal levels of red blood cells, white blood cells, and platelets. 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)

Long-term or late effects of treatment

Medical follow-up is important after treatment for LGL leukemia. 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 chronically low blood counts (for example, anemia, neutropenia, low platelets).
- **Late effects** are medical problems that may appear 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, trouble concentrating, and chronic fatigue.

Living with LGL leukemia 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 LGL leukemia. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.

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1 833 222-4884 • info@bloodcancers.ca • bloodcancers.ca