

# Understanding and managing **acute lymphoblastic leukemia (ALL)**



# What is this booklet for?

This booklet was designed to answer some questions you may have about ALL. It summarizes the treatment options that are available in Canada. It can also serve as a starting point for discussions with your doctor, so that you can decide together what is best for you.

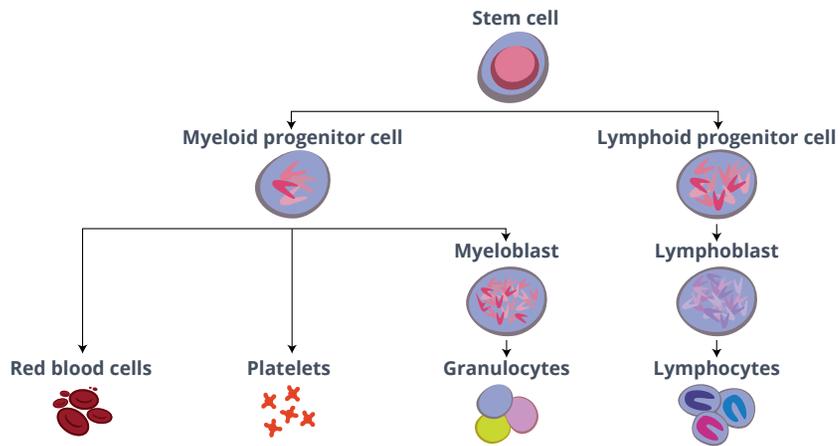
Once you have a better understanding of each treatment option, you can stay informed and take an active role in your ALL treatment process.



# What is ALL?

ALL is a fast-growing blood cancer that starts in disease-fighting **lymphocytes** of your immune system. A lymphocyte is a type of **white blood cell** found in blood and lymph tissue. Lymph tissue includes lymph vessels and lymph nodes.

## Development of blood cells



- All types of blood cells start as stem cells, which can make new cells called “**progenitor cells**” that go on to become specific types of blood cells.
- There are two types of progenitor cells:
  - **Lymphoid**
  - Myeloid
- Both lymphoid and myeloid progenitor cells form into blast cells called **lymphoblasts** or myeloblasts depending on the type.
- Lymphoblasts are supposed to mature into **lymphocytes**, a type of white blood cell.

In ALL, **lymphoblasts grow out of control (leukemia cells)** in bone marrow. This crowds out normal blood cells and prevent them from doing their jobs.

# What are the different types of ALL?

To diagnose ALL, your testing must show that **at least 20% of your bone marrow contains lymphoblasts**. Identifying the subtype of your disease is an important step to planning your treatment. Doctors can identify ALL cells through a unique set of proteins found on the surface of those cells.

## Subtypes:

- **B-cell ALL** is the most common subtype.
  - About **75% of adults** with ALL have this subtype.
- **T-cell ALL** is less common.
  - About **25% of adults** with ALL have this subtype.

ALL can be further divided into subgroups based on changes to your chromosomes and genes. Your doctor will assess these changes to plan your treatment.

Learn more about chromosomes and genes on page 9.



# What are the signs and symptoms of ALL?

If you have ALL, you will likely feel ill because your body is not making enough normal blood cells. You may experience:



**Fatigue, shortness of breath during normal physical activities, dizziness, and pale complexion**

When your red blood cell count is low (anemia)



**Ongoing infections and fever**

When your white blood cell count is low



**Bruising easily, ongoing bleeding from minor cuts, pinhead-sized red spots on your skin, frequent or severe nose bleeds, bleeding gums, and blood in your urine**

When your platelet count is low



**Night sweats**

Possibly a response from your immune system



**Bone or joint discomfort**

When your white blood cells accumulate and cause your bone marrow to expand



**Pain or fullness below the ribs**

When leukemia cells build up in your liver or spleen, causing your abdomen to swell



**Weight loss**

When you are eating less or using more energy

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# What are the possible tests for ALL?

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

## Complete blood count (CBC)

This test measures the number of **red blood cells**, **white blood cells**, and **platelets** in a sample of blood to find out if your counts are high or low. It also measures the levels of **hemoglobin** (a protein that transports oxygen) in your red blood cells.

## Blood and bone marrow tests

These two tests are done to examine bone marrow cells and look for anything unusual with your chromosomes.

- Leukemia starts in the bone marrow. To diagnose ALL, samples of bone marrow must be removed. Lab results will be used to confirm the disease.
- Your bone marrow will also be tested to see how well treatment is working.
- There are two types of bone marrow tests that are often done at the same time.
  - **Bone marrow aspirate**
  - **Bone marrow biopsy**

Your bone marrow is like a sponge holding liquid and cells. An aspirate takes some of the liquid and cells out of the sponge, and a biopsy takes a piece of the sponge.

## Cytogenetic tests

- ALL can cause changes in genes and chromosomes in blood cells.
- Cytogenetic tests look for these changes or abnormalities and are used to learn more about your type of ALL, to target treatment, and to determine the likely path your cancer will take (prognosis).

## Imaging tests

Your doctor may use x-rays, computed tomography (CT) scans, magnetic resonance imaging (MRI) scans or positron emission tomography (PET) scans to look at your tissues and organs in more detail.

### X-rays and CT scan

- An x-ray is a type of radiation. In small doses, it is used to make pictures of the inside of the body.
- A CT scan uses x-rays and computer technology to take pictures of the inside of the body. It takes many x-rays of the same body part from different angles.
  - All the images are combined to make one detailed picture.

### MRI scan

- An MRI scan uses magnetic fields and radio waves to create images of your organs and tissues.
- Doctors may request a scan of your head and/or spinal cord to look for changes in the bone marrow.

DNA is the material that carries all the information about how our bodies look and function. Each piece of information is carried on a different section of the DNA and these sections are called “genes.” Genes tell a cell how to make a specific protein, which is used by the cell to grow and survive. DNA is organized into tightly coiled thread-like bundles called “chromosomes” that contain thousands of genes. Some changes, called “mutations,” can happen in your genes.

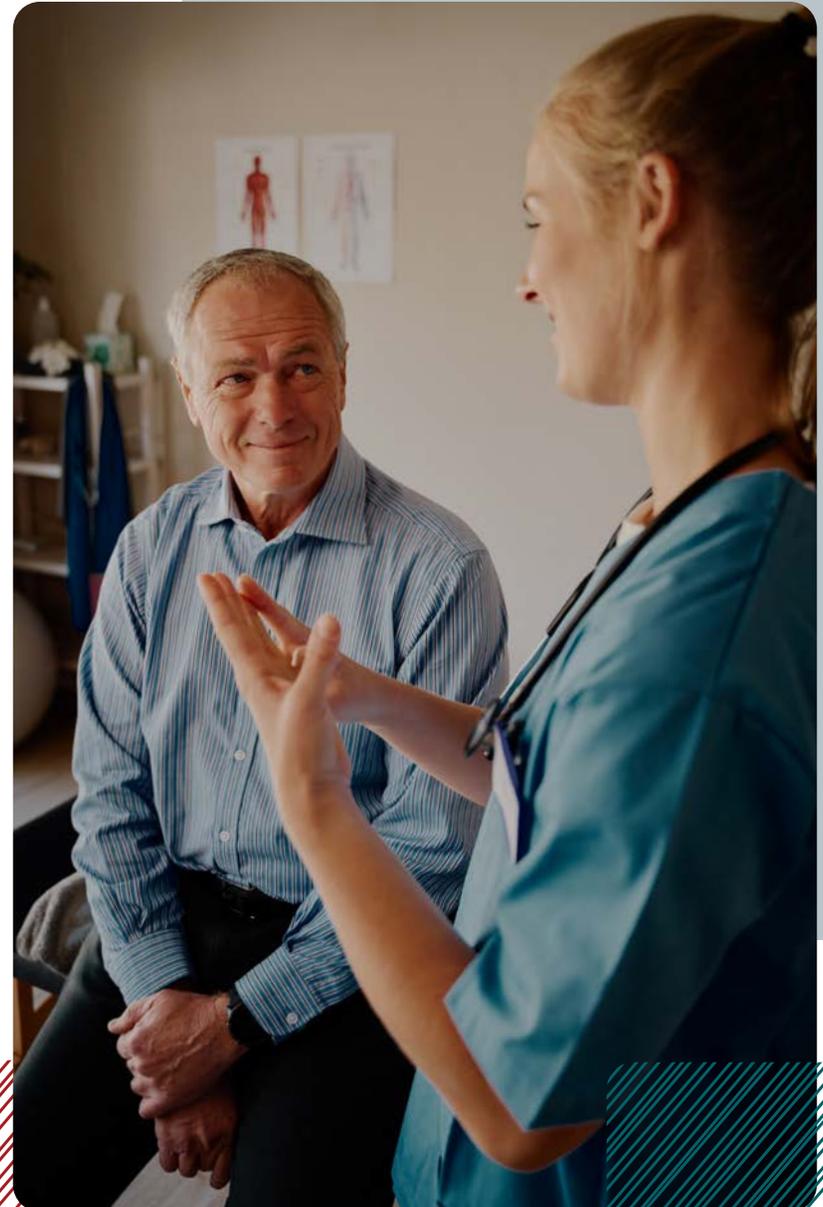
# How is ALL treated?

## Factors affecting treatment choice for ALL

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:

- Age
- ALL subtype
- Chromosome and/or genetic changes
- Leukemia cells in your brain and spinal cord fluid
- Number of white blood cells in the blood at the time of diagnosis
- Response to the first phase of chemotherapy

Not everyone receives the same treatment. After considering the above factors, your doctor will determine the type of treatment that is most appropriate for you and may recommend one or more of the treatment options listed on pages 12 and 13.



# What treatment options are available for ALL?

Your treatment is focused on destroying as many leukemia cells as possible. When you no longer have evidence of leukemia cells in your body, you are said to be in **remission**. Even with complete remission, some leukemia cells cannot be seen with a microscope and may still be in your body. This is known as minimal residual disease (MRD).

Let's take a closer look at the available treatment options for ALL.

## Treatment options for ALL

### Chemotherapy

- Uses medicine (chemicals) to kill cancer cells.
- Long-term chemotherapy is the current standard treatment for ALL. It includes three phases:
  - **Phase 1: Induction therapy** aims to destroy as many leukemia cells as possible so you can go into remission.
  - **Phase 2: Consolidation therapy** aims to kill any remaining ALL cells after you go into remission.
  - **Phase 3: Maintenance therapy** aims to prevent the disease from returning.

### Targeted therapy

- Uses drugs or other substances to target and attack specific cancer cells.
- These treatments are usually less likely to harm normal cells.
- **Tyrosine kinase inhibitor:**
  - Blocks the signals that cause cancer to grow and spread.
  - Might be used alone or in combination with other systemic therapies like chemotherapy.

Joining a clinical trial can be a good option for you. A clinical trial is a type of research that studies a test or treatment in people. It gives people access to healthcare options that otherwise wouldn't be available. Ask your medical team if there is an open clinical trial that is right for you.

### Immunotherapy

- This is a targeted therapy that increases the activity of your immune system.
- By doing so, it improves your body's ability to find and destroy cancer cells.
- **Monoclonal antibody therapy:**
  - Monoclonal antibodies are a type of antibody made in the lab.
  - In cancer treatment, monoclonal antibodies may kill cancer or leukemia cells directly.
  - They may block development of tumor blood vessels, or they may help the immune system kill cancer cells.

### Radiation therapy

- Uses high-energy radiation from x-rays, gamma rays, protons, and other sources to kill cancer cells and shrink tumors.
- It is given over a certain period of time.
- It can be given alone or with certain systemic therapies.
- It may also be used as supportive care to help ease pain or discomfort caused by cancer.

### Stem cell transplantation (SCT)

- Only an allogeneic SCT is used as a treatment option for ALL.
- This is a procedure in which stem cells from another person (a donor) are infused into your body.
- Before an SCT, treatment is needed to destroy bone marrow cells. This is called **conditioning** and it creates room for the healthy donor stem cells.
  - It also weakens the immune system so your body won't kill the transplanted cells.
- After conditioning, you will receive the healthy stem cells through a transfusion.
- A transfusion is a slow injection of blood products into a vein. This can take several hours.
- The transplanted stem cells will travel to your bone marrow and grow. New, healthy blood cells will form.



# What questions should you ask your doctor?



Being an active participant in your cancer care can give you and your family a greater sense of control. One way to achieve this is by building a relationship with your medical team based on open communication.

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

## Diagnosis

- What type of ALL do I have? What does this mean in terms of prognosis and treatment options?
- What tests are needed? What other tests do you recommend?
- 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?
- Will treatment start before the test results are in?

## General treatment

- What are the treatment choices? What are the benefits and risks?
- Which treatment do you recommend and why?
- How long do I have to decide?
- Will I have to go to the hospital or elsewhere for treatment? How often? How long is each visit?
- Will I have to stay overnight in the hospital or make travel plans?
- Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?

## Treatment options

- What will happen if I do nothing?
- How do age, white blood cell count, health, and other factors affect the options?
- Am I a candidate for a stem cell transplant?
- Which option is proven to work best for my ALL subtype, age, and other risk factors?
- How do you know if treatment is working?
- What are my options if the treatment stops working?

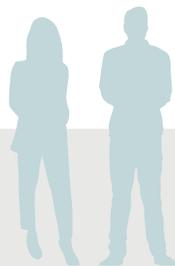
## Side effects of treatment

- What are the possible risks or side effects of my treatment? How serious are they and what should I report right away?
- How can I manage the side effects?

## Other considerations

- Should I still take the other medications I am on?
- Is it okay to continue with the supplements I am currently taking?
- What costs will I encounter?
- In cases of emergency, how can I reach your office on nights, holidays, or weekends?

**Be sure to write down any questions you have that are not on this list. For instance, you may want to ask about qualifying for clinical trials.**



## What resource is available to you?



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LYMPHOMA  
SOCIETY OF  
CANADA®

Visit our website to learn more about ALL and its treatment.

**bloodcancers.ca**

For more information, never hesitate to contact us. We're here to help you!



**1 833 222-4884**



**info@bloodcancers.ca**

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LLS Health Manager™ app by visiting

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You can use this app to note down any questions that you may have to bring to your next doctor's appointment.



