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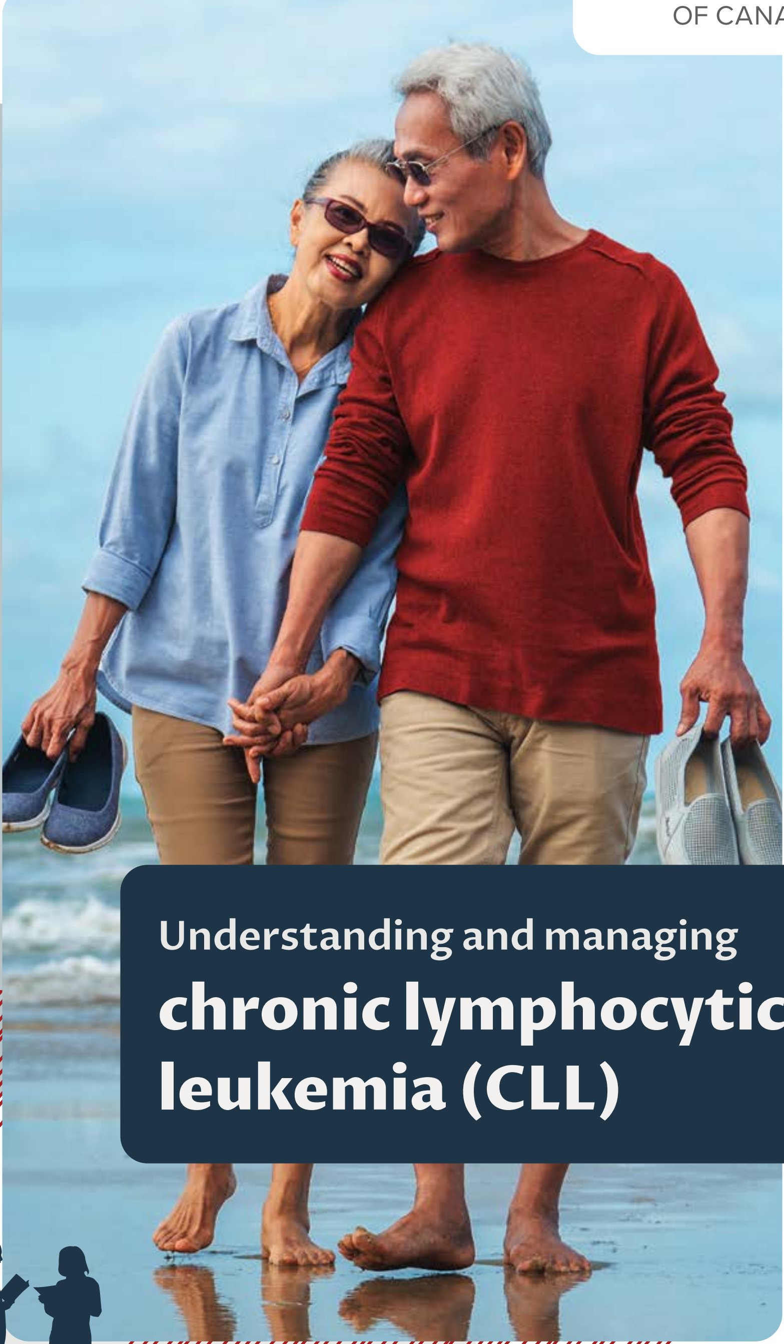


Understanding and managing

chronic lymphocytic leukemia (CLL)

Kathy, NS

"My journey with chronic lymphocytic leukemia hasn't been easy, but all-in-all it has been fairly positive. I was diagnosed with CLL in August 2009 through routine blood work and was put on "watch and wait" for four years. At the time, it was hard to know that I wouldn't receive treatment right away, and that I was supposed to go on with my life as normal. That was very nerve-racking to say the least. The Internet was really my only source of information and it wasn't always helpful or reliable.

Nine months into my CLL journey, I discovered one of my neighbours had been living with it for the past 10 years. I knocked on his door and was immediately ushered in for coffee and a long chat. I listened to his stories of ups and downs, his treatments, and how he coped and still managed to enjoy his life. I came away feeling a great weight had been lifted from my shoulders. A year later, I discovered a support group for blood cancers. It was a great place to compare symptoms and find ways for managing stress, fatigue, fear and more. It was comforting to talk to others who were going through the same things. It was so nice to know that I wasn't alone.

For this reason, when I heard about the LLSC's peer support program, I immediately signed up as a volunteer. Over the past few years, I've chatted with several others through the program and find we have many of the same fears and feelings.

In October 2013, I began treatment. After six rounds of treatment with minimal side effects, no CLL cells were detectable in my blood. I can still do all the things I enjoy – walking, swimming, camping, reading, sewing, travelling – I just have to do some of them a little differently. I had the best results one could hope for after treatment and now seven years later my blood counts are still holding.

I've lived in Halifax all my life. Today, I am enjoying time with my husband and our two beautiful adult children and their families."

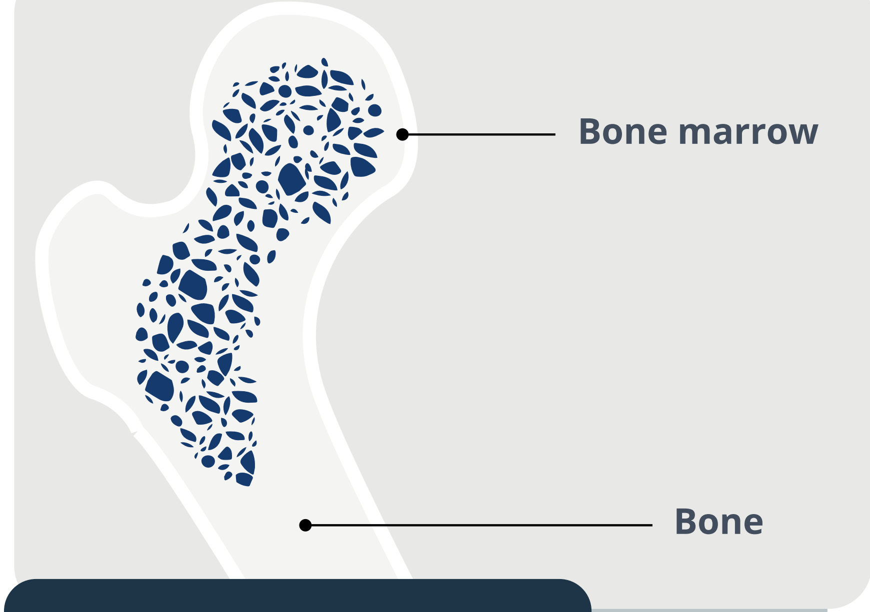
What is this booklet for?

This booklet was designed to answer some questions you may have about CLL. 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 CLL treatment process.

What is CLL?

Cancer can affect different areas of the body. CLL is a type of cancer that affects white blood cells called B lymphocytes. These lymphocytes are made in your bone marrow – the soft inner part of your bones. If you have CLL, your body makes abnormal lymphocytes that accumulate in your blood and other organs.



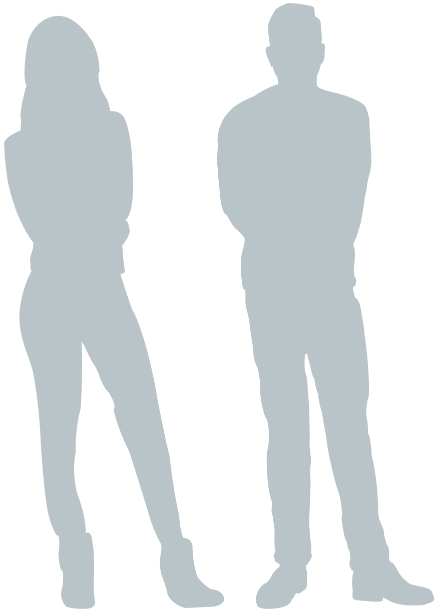
CLL is the most common type of adult leukemia in Canada.

What are the different forms of CLL?

CLL can be slow growing and need no immediate treatment. Another form can grow at a faster rate, requiring treatment right away.

- **The slower-growing form** has an increased number of lymphocytes but a normal or slightly below normal level of red blood cells, platelets (clot forming cells) and neutrophils (another type of white cell) in the blood. This form can remain stable for years.
- **The faster-growing form** has too many lymphocytes that block normal cell production. As a result, the number of red blood cells and platelet levels drop lower than normal, causing a variety of symptoms.

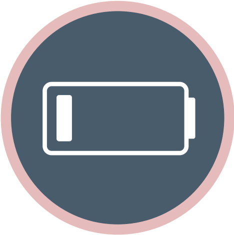
CLL cells can spread from your bone marrow to your lymph nodes, spleen, or liver, and cause these organs to enlarge. Ask your healthcare provider which form of CLL you have.



What are the signs and symptoms of CLL?

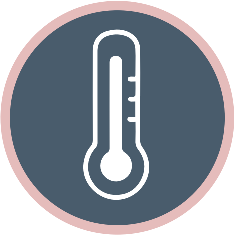
The majority of people have no symptoms when they are diagnosed with CLL. Later, signs and symptoms may occur. Many people with CLL will live for years without symptoms. Check with your doctor if you have any of the following:

Painless swelling of
the lymph nodes in the neck,
underarm, stomach, or groin



Fatigue

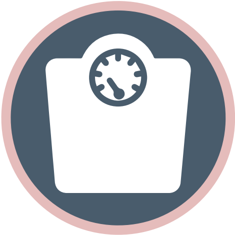
Pain or fullness
below the ribs



Fever
and infection

Flat, pinpoint,
dark red spots under the skin
caused by bleeding

Easy bruising or bleeding



Weight loss for
no known reason

What are the tests for CLL?

Blood test

Often, CLL is suspected after a routine blood test. A complete blood count (CBC) measures the components of the blood. Test results include counts of white blood cells, red blood cells, and platelets. Your white blood cell counts may be high. More blood tests are needed to confirm CLL.

Molecular tests

In addition to blood tests, doctors may order molecular tests to find out what chromosome abnormalities and genetic changes are present in your CLL cells. These tests can usually be performed on a blood sample. However, if a bone marrow sample is being taken, it can also be used to perform molecular genetic testing. Results of molecular genetic testing can predict how quickly the disease will progress and can help determine your best available treatment options.

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.

Fluorescent *in situ* hybridization (FISH) test

Your doctor may take a blood sample to test for something called a “del(17p)” change to look for a loss of a particular portion in your gene. **FISH test uses special dyes that help identify this change in the genetic material of cancer cells by making it glow (fluoresce) so that it is easier to see**. Before starting first-line treatment, your doctor may want to test for the “del(17p)” change in your DNA.

TP53 test

Your doctor may also use a TP53 test to look for changes in the *TP53* gene (called a “*TP53* gene mutation”). *TP53* gene is often mutated in those with “del(17p)”, but can be found in others too. Before starting first-line treatment, your doctor may want to test for “*TP53* gene mutation” in your DNA. Chemotherapy does not work well for those who have CLL with a “del(17p)” or “*TP53* gene mutation.”

Immunoglobulin heavy-chain variable region (IGHV) test

Your body makes substances called “antibodies” to attack viruses and bacteria. Your DNA has a region called *IGHV* that contains instructions for making certain parts of these antibodies. There may or may not be changes associated with this *IGHV* gene in people with CLL. Before starting first-line treatment, your doctor may want to test for *IGHV* mutation in your DNA. Around 60% of people with CLL in need of treatment have an unmutated *IGHV* status.

Ask your doctor about molecular tests. The results of these tests can help doctors assess the outcome of CLL and plan your treatment accordingly.

What factors will determine treatment options for your CLL?

The goals of treatment are to achieve a long-term remission and stop CLL from growing. Treatment options and recommendations depend on several factors:

- Your results of genetic analysis
- Your red blood cell, white blood cell, and platelet blood counts
- Whether your liver, spleen, or lymph nodes are larger than normal
- Whether you have signs or symptoms, such as tiredness, fever, chills, or weight loss
- Your response to the first-line treatment
- Whether the CLL has come back
- Your age
- Your overall health
- Your preferences

After considering the above factors, your doctor will recommend one or more of the treatment options listed on pages 13–17.

What treatment options are available for CLL?

Not everyone receives the same treatment. Various factors (listed on the previous page) will help your doctor determine the types of treatments that are most appropriate for you. Speak with your doctor to help you make informed decisions.

First-line treatment

The first treatment your doctor gives you for your CLL can also be referred to as a “first-line” treatment.

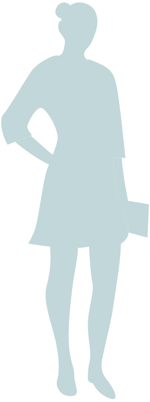
Second-line treatment

If your disease comes back, or if the first-line treatment no longer works, your doctor may decide to give you another one, otherwise known as a “second-line” treatment. This decision will depend on your overall health, what the first-line treatment was, and how well it worked.

- If the initial response to the “first-line” treatment lasted a long time (usually at least a few years), the same treatment might be used again.
- If the initial response wasn’t long-lasting, using the same treatment may not be as helpful and therefore treatment options should be discussed with your doctor.

Many drugs and combinations may be second-line treatment options. Targeted therapy and antibody therapy are commonly used, alone or in combination. Your doctor may also try other chemo drugs.

Now let’s take a closer look at the available CLL treatment options.



Treatment options for CLL

Treatment option	**Watch & Wait (or Active Surveillance)**
What it does	**Watch & Wait (or Active Surveillance)** is closely monitoring your condition without giving any treatment until signs or symptoms appear or change.
Line of treatment	Before any treatment.
Mode of administration	Not applicable.
Treatment duration	As needed.

Treatment options for CLL

Treatment option	Chemotherapy
What it does	• Chemotherapy is a cancer treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. • When chemotherapy is taken by mouth or injected into a vein or muscle, the drugs enter the bloodstream and can reach cancer cells throughout the body (systemic chemotherapy). • It cannot tell the difference between cancer cells and normal cells.
Line of treatment	This is the first-line treatment option when there is no "del(17p)/*TP53* gene mutation."
Mode of administration	This type of treatment is either taken by mouth or given by needle directly into a vein (intravenous infusion).
Treatment duration	The full course of chemotherapy (the total number of cycles) may take several months.

Cancer cells tend to grow and divide quickly, which makes them good targets for chemotherapy.

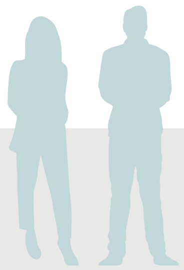
Treatment option	Targeted therapy
What it does	• Some drugs target specific proteins in cancer cells that are not found in normal cells. • For this reason, it usually causes less harm to normal cells than chemotherapy or radiation therapy do. • Examples include Bruton's tyrosine kinase (BTK) inhibitors and BCL-2 inhibitors.
Line of treatment	This is an option for first-line and next-in-line treatments.
Mode of administration	This type of treatment is available in a pill form, which makes it easier for those with CLL to take them at home.
Treatment duration	Some drugs need to be taken for life and some have a fixed treatment duration.

This type of therapy uses drugs or other substances to identify and attack specific cancer cells.

Treatment options for CLL

Treatment option	**Antibody therapy (or Immunotherapy)**
What it does	• Antibodies are proteins in our blood that fight infections. They are made naturally by our lymphocytes when we get an infection. They stick to proteins on the surface of bacteria and viruses and tell our body to get rid of them. • Monoclonal antibodies are molecules that are made in the laboratory. They are designed to recognize and attach to a specific part of a particular molecule on cancer cells. When a monoclonal antibody attaches to a cancer cell, it can stop or slow down its growth or it can signal to the immune system to recognize the cell and kill it.
Line of treatment	This is an option for first-line and next-in-line treatments.
Mode of administration	This type of treatment is given by needle directly into a vein (intravenous infusion) or under the skin (subcutaneous).
Treatment duration	Antibody therapy is most often given in combination with chemotherapy OR oral targeted therapy.

Treatment option	**Stem cell transplantation (SCT)**
What it does	• SCT involves a rescue with stem cells which is commonly called a transplant. Stem cells from a compatible donor (allogeneic transplant) are used to replenish those destroyed by the intensive treatments such as high dose chemotherapy and whole-body radiation. • Allogeneic SCT is helpful for some people with CLL. SCT is usually done as part of a clinical trial in the younger population with high-risk genetic changes or relapsed/refractory disease (disease that returns after treatment or does not respond to treatment).
Line of treatment	Some people who have a very high-risk disease may be referred for possible SCT early in treatment.
Mode of administration	
Treatment duration	



What else should you know about your CLL treatment?

Treatment until progression

If you are being given a "treatment until progression," this means that your treatment will be given continuously until your disease no longer responds to it or until you experience unacceptable side effects. A first-line or second-line treatment may fit under this category.

Fixed-duration treatment

If you are being given a "fixed-duration treatment," this means that your treatment will be given for a fixed amount of time, usually for a set number of days, weeks, or months. A first-line or second-line treatment may fit under this category.

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 health care that otherwise couldn't usually be received. Ask your treatment team if there is an open clinical trial that you can join.

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 care team based on open communication.

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

Diagnosis

- What type of cancer do I have? From what type of cell did it form? Is this cancer common?
- Will I need to have other tests before we can decide on treatment?
- What tests do you recommend for me?
- Where will the tests take place? How long will the tests take?

General treatment

- Can I just carefully monitor the cancer?
- Should I start treatment now? Why or why not?
- What should I do to be ready for treatment?
- What are my treatment options?
- Which one do you recommend for me? Why?
- What is the treatment frequency?
- How often will you test my blood or bone marrow to see how treatment is 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

- Can treatments be taken at home?
- How will treatment affect my daily activities?
- What if I miss a treatment?
- Are there any limits on what I can do?
- Are there any foods or beverages I should or should not eat?
- 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 might want information about how you'll feel so that you can plan your work schedule. Or you may want to ask about qualifying for clinical trials.

What resource is available to you?

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

bloodcancers.ca

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

1 833 222-4884

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Please download the
LLS Health Manager™ app by visiting

bloodcancers.ca/health-manager-app

You can use this app to note
down any questions that you may
have to bring to your next
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