

Understanding CLL & SLL

A Patient's Guide to
**CHRONIC LYMPHOCYTIC LEUKEMIA AND
SMALL LYMPHOCYTIC LYMPHOMA**



LYMPHOMA
CANADA

Lymphoma Canada wishes to acknowledge all the individuals who contributed to the content and development of this publication. Dedicated members of Lymphoma Canada's Scientific Advisory Board, Nursing Advisory Board and Patient & Family Advisory Committee provided their expertise, advice, and editorial input to ensure the accuracy and relevance of the information. We thank these caring individuals; their input was invaluable. We hope this manual will provide those diagnosed with CLL or SLL with the information necessary to better understand their illness and feel confident and empowered as they continue on their journey.

INTRODUCTION

Getting a cancer diagnosis is an overwhelming experience. It is perfectly normal to be shocked by the diagnosis, anxious about the future, and confused about the medical information and decisions that need to be made.

If you were recently diagnosed with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL), you probably have many questions about the disease, how it is treated and what your future will look like.

The information in this booklet is meant to act as a guide. It will help you understand the nature of CLL and SLL and what to expect from treatments, including any possible side effects. The more you know about your disease, the more confident you will be in making decisions with your doctors about your care and wellbeing.

Information. Help. Hope.

You don't have to face CLL or SLL alone. Lymphoma Canada connects patients, their family and friends, medical professionals, researchers, volunteers, and donors to build a strong community.

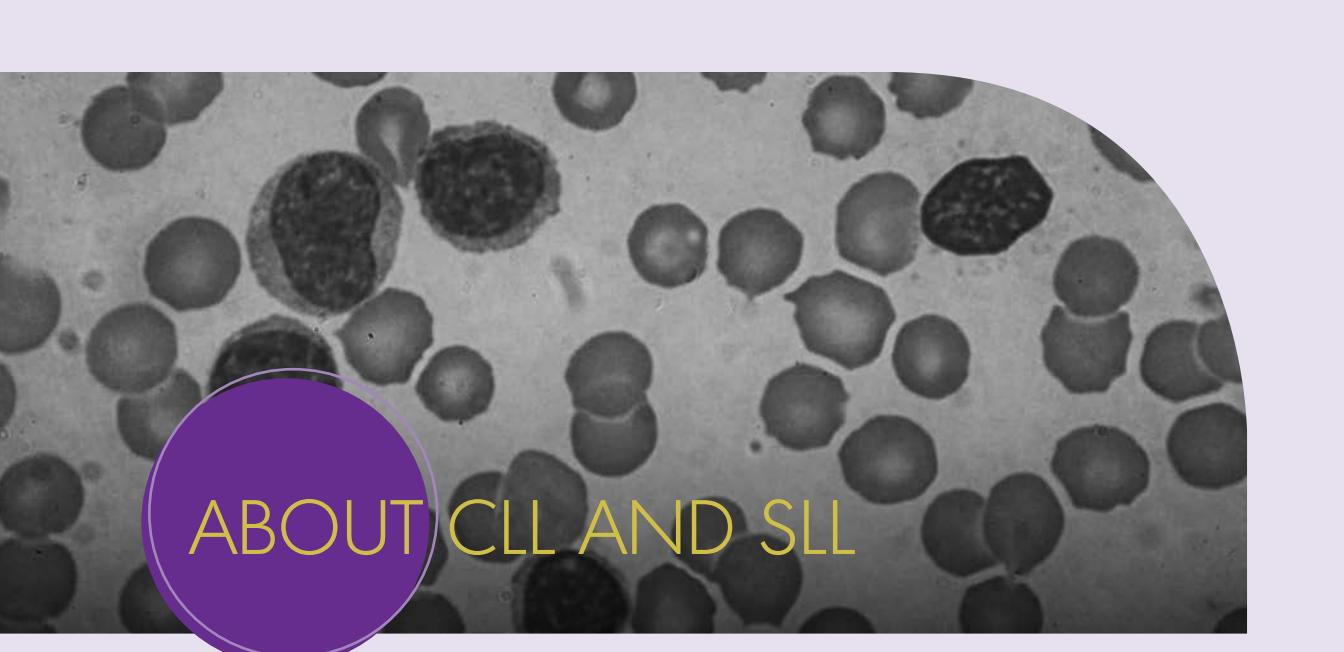
- A community that conducts research to learn lymphoma's causes, to develop better treatments, and to find a cure.
- A community that helps people talk about and cope with the fifth most common cancer in Canada.
- A community that invites you to get and give support.

For more information about our educational and support programs, please visit www.lymphoma.ca or call 1.866.659.5556.

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A black and white microscopic image showing a dense population of various blood cells, including red blood cells and larger, more irregularly shaped cells, possibly platelets or blasts, against a light background.

ABOUT CLL AND SLL

Being diagnosed with cancer is often overwhelming. Learning more about the disease can ease confusion and allow you to feel more in control.

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CLL (chronic lymphocytic leukemia) and SLL (small lymphocytic lymphoma), are cancers of the blood and lymphatic systems.

To better understand CLL or SLL and how it may affect you, it helps to have a basic understanding of the lymphatic system and cancer in general.

Cancer

Cancer is the uncontrolled growth of abnormal cells.

Cells make up every part of your body: skin, hair, nails, lymph nodes, blood and body organs. To keep things running smoothly, cells grow, work, and divide in a very controlled fashion. All of these cells also eventually die.

Normally, a cell dies when it becomes too old or when it stops working properly. The immune system is also constantly monitoring cells throughout the body to identify abnormal cells and destroy them.

When damage to a cell gives it the ability to avoid death or if the immune system doesn't work properly, some cells can live longer than normal. These abnormal cells can multiply and may cause cancer.

Abnormal cells often cannot properly perform their regular job.

Most cancers are named after the organ or the type of cell they start growing in. For example, a cancer that starts in the pancreas is called

pancreatic cancer and a cancer that starts in lymphocytes is called lymphoma.

The Lymphatic System

The lymphatic system is part of your circulatory system and serves many life-preserving functions. It is made up of a network of vessels, nodes and organs that run throughout your body.

The main components of the lymphatic system are:

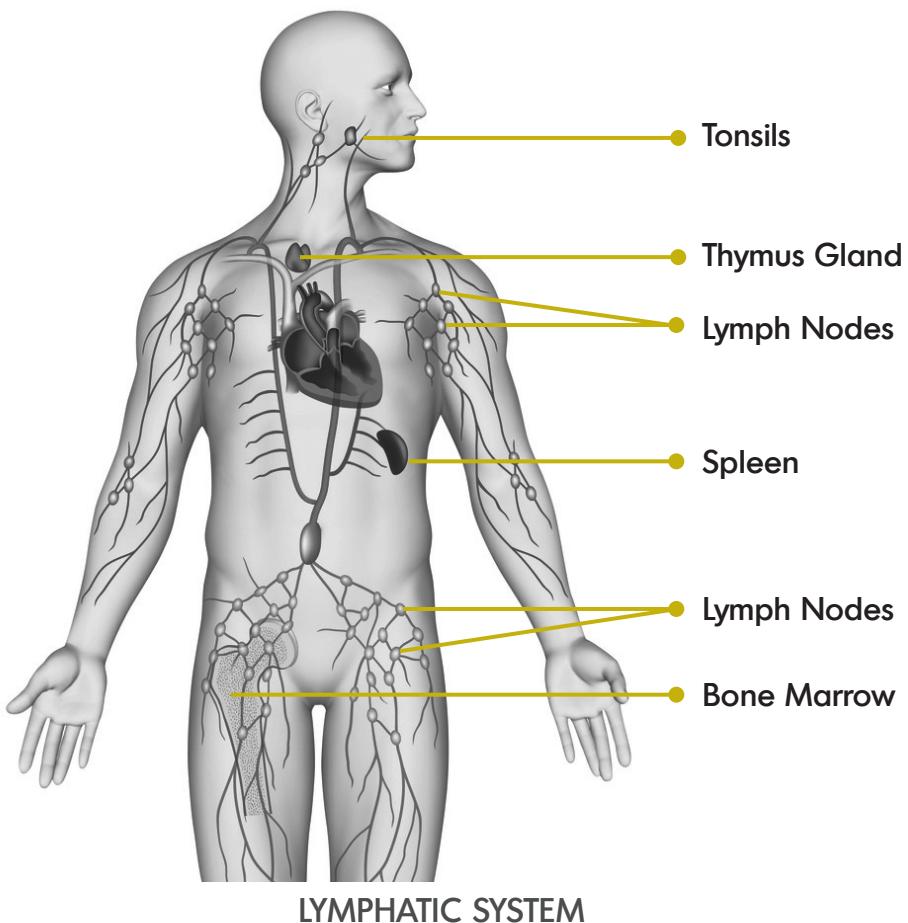
- **Lymph:** the fluid that circulates within the lymphatic system.
- **Lymphatic vessels:** vessels that circulate lymphatic fluid (also called lymph) throughout the body.
- **Lymph nodes:** small, bean-shaped organs that filter circulating lymph. There are hundreds of lymph nodes throughout your body, often in groups, including in the neck, armpits, chest, abdomen, groin and elbows.
- **Bone marrow:** soft, spongy tissue in the bones where blood cells are made.
- **Spleen:** an organ in the abdomen that is involved in the production, storage and removal of blood cells.
- **Thymus gland:** the organ where T lymphocytes develop and mature.

Two very important functions of the lymphatic system are:

1. **To defend the body against infection.** The vessels of the lymphatic system move lymph (fluid) throughout the body. As it travels through the lymphatic vessels, the lymph passes through lymph nodes, which are primarily made up of lymphocytes (a type of white blood cell).

Harmful organisms, like bacteria and viruses, are trapped and destroyed by the lymphocytes in the lymph nodes. This helps keep the body free of infection.

2. **To circulate and regulate fluid levels in the body.** The small vessels of the lymphatic system absorb fluid from surrounding tissues throughout the body and return it to the bloodstream. This helps to prevent edema (swelling due to excess fluid) and keeps the fluid levels in the body and the bloodstream at healthy levels.



If a large number of foreign substances are filtered through a node or series of nodes, swelling may occur and the nodes may become tender to the touch. Most swollen nodes are a reaction to infection and are not cancerous.

WHAT ARE LYMPHOCYTES?

Lymphocytes are a type of white blood cell and are a major part of the lymphatic system. Together with other cells of the immune system, they work to fight infection and prevent disease. Lymphocytes can be found in the blood and marrow; however, most of them are normally circulating in the lymphatic system. There are three main types of lymphocytes:

1. B lymphocytes (B cells) make antibodies to fight infections. They are called B cells because they mature in the Bone marrow.
2. T lymphocytes (T cells) destroy virus-infected cells and tumour cells; they also help other white blood cells carry out immune processes. They are called T cells because they mature in the Thymus gland.
3. Natural killer cells (NK cells) destroy virus-infected cells and tumour cells.

CLL and SLL

CLL and SLL are two forms of the same illness and they are treated in the same way.

If you have SLL, the information here will therefore apply to your illness too. Both forms will be described together as 'CLL' unless there is something different about SLL that is important to highlight.

CLL (chronic lymphocytic leukemia) is a type of blood cancer. In people with CLL, the body makes too many abnormal lymphocytes. These abnormal lymphocytes look normal under a microscope, but they do not fight infections like healthy lymphocytes do.

Although it is called leukemia, CLL is a type of blood cancer called lymphoma. Thinking of CLL as a lymphoma is important, because CLL behaves and is treated like other indolent (slow-growing) lymphomas.

CLL is very similar to SLL (small lymphocytic lymphoma) and the two are generally considered the same disease. The difference between CLL and SLL is where the cancer cells collect. When most of the cancer cells are in the blood stream and the bone marrow, it is called CLL. When the cancer cells are mostly found in the lymph nodes, it is called SLL.

CLL usually progress slowly. In many cases, it causes few, if any problems in its early stages. Many people have CLL that is slow growing and they may have stable disease for years with few or no symptoms. Other people with CLL have a faster-growing form of the disease that may cause more symptoms and need treatment sooner.

You may be diagnosed with SLL first, but doctors may later start calling your condition CLL if the number of lymphocytes in your blood (white cell count) rises. This is nothing to be alarmed about and doesn't mean the disease has changed or 'transformed' in any way.

How Common is CLL?

Over 2,200 people in Canada are diagnosed with CLL each year. CLL is more common in men and occurs mainly in people aged over 60, with the average age of diagnosis in the early-70s.

It is not known what causes CLL. You can't catch it from, or pass it on to, someone else. Nothing you have done has caused the CLL to develop.

Risk Factors

Anything that increases a person's risk for contracting a disease is called a risk factor. Unlike other forms of cancer, CLL has few known risk factors.

Although people with CLL are more likely than others to have a family member with CLL or with another type of lymphoma, it is not an inherited disease. Most people who have a relative with CLL will never have CLL themselves.

Some studies suggest that certain environmental factors might play a role in the development of CLL, including exposure to some chemicals (herbicides and insecticides).

Monoclonal B-cell lymphocytosis (MBL) is diagnosed when patients have a small number of cells with the characteristics of CLL cells in their blood and do not have any CLL symptoms or signs of lymph node, spleen or liver enlargement. A small percentage of these patients will go on to develop CLL.

It is important to remember that even if you have one or more risk factors, you will not necessarily develop CLL. In fact, most people with risk factors never develop the disease and many who are diagnosed have no known risk factors.

Development of CLL

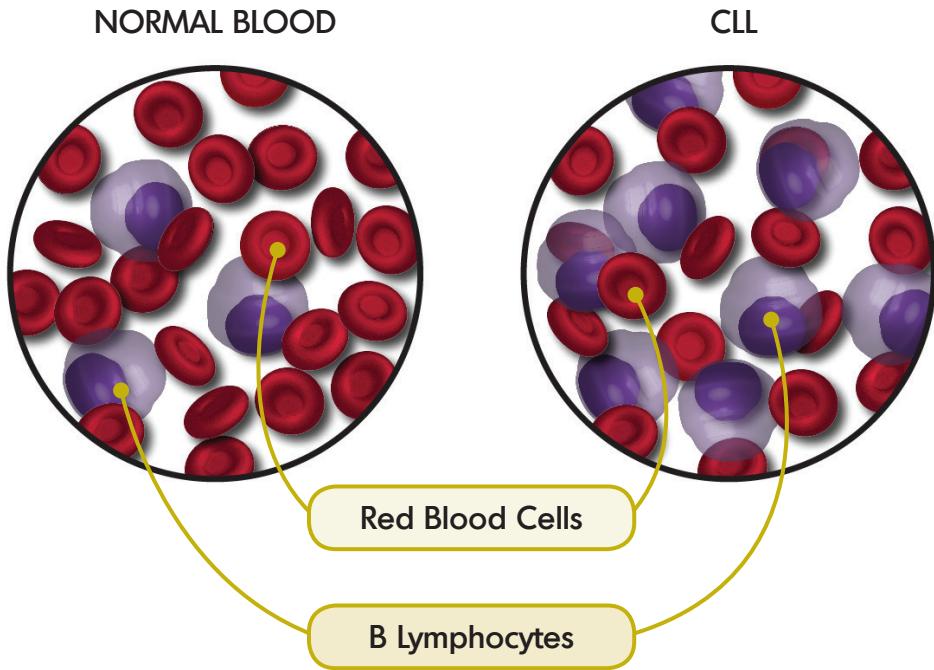
Blood is made up of blood cells floating in plasma. Plasma is the liquid part of your blood and is mostly made of water.

There are three basic types of mature blood cells or components:

1. **Red blood cells (also called erythrocytes).** They make up almost half of blood. Red blood cells are filled with hemoglobin. Hemoglobin is a protein that picks up oxygen in the lungs and delivers it to cells all around the body.
2. **White blood cells (also called leukocytes).** They fight disease and infection by attacking and killing germs that get into the body. There are several kinds of white blood cells. Each kind fights germs in different ways. **B lymphocytes (B cells)** are the type of white blood cell that becomes cancerous in CLL.
3. **Platelets (also called thrombocytes).** They are small pieces of cell that help blood clot and stop bleeding.

Blood cells are made in the bone marrow. Bone marrow is the soft inner part of some bones. Bone marrow contains blood stem cells that can grow into all 3 types of mature blood cells. When blood cells are fully formed and functional, they leave the bone marrow and enter the blood. When these cells grow old, they die naturally and are continuously replaced by new cells.

Although the exact cause of CLL is unknown, CLL occurs when there is damage to the genes of developing lymphocytes in the bone marrow. This damage changes the normal lifespan of the lymphocytes and they do not die as planned. The increasing number of CLL cells in the blood and bone marrow crowd out healthy blood cells. This can disrupt the ability of the healthy blood cells to carry out their regular functions.



DIFFERENCE BETWEEN NORMAL BLOOD AND CLL

How CLL Affects the Body

CLL cells can collect in the blood, bone marrow, lymph nodes, spleen, liver and other organs.

If CLL cells collect in the bone marrow in large numbers they can stop the bone marrow from making enough healthy blood cells. This can cause:

- Low numbers of red blood cells (anemia), which can cause fatigue or tiredness.
- Low numbers of platelets (thrombocytopenia), which can cause unexplained bruising or bleeding.
- Low numbers of white blood cells called neutrophils (neutropenia), which can lead to more frequent or long-lasting infections. These infections can be life threatening.

CLL also stops the immune system from working properly, so that it:

- Doesn't react against bacteria and viruses as well as it should, making you more likely to have infections.
- Can start to attack your body's own blood cells, such as your red blood cells or platelets – this is called autoimmunity.

Signs and Symptoms

A symptom is anything unusual in a normal body function, appearance, or sensation that a patient experiences. Patients should report all of their symptoms to their doctor or nurse. Some patients with CLL do not experience any symptoms.

Signs are anything unusual that doctors or nurses notice when they examine their patients.

Frequently, a diagnosis is made when blood tests are performed as part of a routine annual check-up. An unexplained high lymphocyte count is the most common sign that leads a doctor to consider a CLL diagnosis.

As the cancerous cells build up in the body, some people will start to notice symptoms.

COMMON SYMPTOMS OF CLL

Symptom	Possible cause
Tiring more easily/ fatigue	People may have less energy due to fewer healthy red blood cells (anemia) and more cancerous cells.
Swollen lymph nodes or spleen	High numbers of cancer cells can gather in the lymph nodes or spleen. As the lymph nodes increase in size they can become tender or uncomfortable. An enlarged spleen may cause abdominal discomfort/bloating or a sense of feeling full after eating a relatively small amount of food.

Infections	Infections may occur more often because cancer cells cannot fight off infection like healthy lymphocytes.
Weight loss	Cancer itself uses up energy or calories that your body would otherwise use or store, so you may lose weight. Some people with CLL lose weight because their spleen is pressing on their stomach so they feel full faster and therefore eat less.
Night sweats	The exact cause of these drenching night sweats, enough to soak your pajamas, are unknown.

Keep in mind that none of the symptoms listed are specific to CLL; these symptoms are also common to other illnesses.

During the visit with the doctor, you should describe all your symptoms. The doctor will ask detailed questions about medical history and perform a complete physical examination.



YOUR MEDICAL TEAM

Your team of doctors, nurses and social workers are valuable sources of support as you cope with a CLL diagnosis. The relationship you have with your medical team can make a big difference in how you cope with the challenges of your diagnosis and manage your care.

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All of the professionals you see, including the specialists, make up your medical team.

The treatment of CLL is usually overseen by a medical oncologist (a doctor who treats cancer) or a hematologist (a doctor who treats blood cancers and other blood diseases). Depending on your healthcare needs, you may also see other specialists such as a radiation oncologist or surgeon. You will also interact with other healthcare professionals such as an oncology nurse, nurse practitioner, radiation therapist, physician assistant, pharmacist, social worker, and registered dietitian. Your medical team will work together and communicate with you to plan, carry out, and monitor treatment.

Taking an Active Role

It can be very overwhelming to learn that you have cancer, and treating cancer can be a complex process. You may have many questions as you go through the different stages. Often one of the challenges is understanding all the information about your disease and treatment options so you can make the best decisions, along with your doctors. It is important that you are involved in the development of your treatment plan.

Being an active participant in your cancer care can give you and your family a greater sense of control over the situation. One way to become an active participant in your care is to build a good relationship with your medical care team. A good partnership with your care team is based on

open and effective communication. You and your doctor should trust and respect one another and work together to make the best decisions for you.

Communicating with Your Medical Team

Even if you have a good relationship with your medical team, talking about your cancer experience can be a challenge. However, good communication with your doctors and nurses is important for many reasons. It can help with:

- Gathering clear information about the disease
- Understanding your treatment options
- Making informed decisions about care
- Preparing for and managing side effects
- Expressing feelings and concerns
- Feeling more in control of the situation
- Feeling confident about your care

“Nobody has helped me the way you (Lymphoma Canada) have. Just being able to talk to you and sort through next steps and how to speak with the medical staff is a huge help – I really didn’t know how to handle this...I was struggling with how to communicate with the doctor.”

Anonymous,
patient

The following are some tips to help you communicate effectively with your cancer care team:

Find out what works for you. Each person's communication style is different and what works for one may not work for another. Some people feel more in control and empowered when they know all of the details. Others find all the information to be overwhelming. Still others would prefer information they can take home and read about on their own time. Decide how much or how little information you want to know, and let your doctor know.

Speak up. You know yourself better than anyone else. It's important to keep your medical team fully informed about how you are coping, and any new or unusual symptoms you may be experiencing (e.g., changes in your sleep, bowel habits, mood, appetite, memory, sexual function). Communicating your needs will give your medical team a clearer picture of your situation so they can address your needs and formulate a more individualized treatment plan.

Educate yourself. Learning about cancer is like learning another language. When you understand the language, communication improves between you and your medical team. Ask your doctor if there is written information that you can take home with you. Look at www.lymphoma.ca. By having knowledge about your disease and treatment options, you will be better able to make informed decisions.

Keep files and records. Staying organized is an important component of cancer care. Keep a record of your medical history, medications, test results, and symptoms. Also, keep a calendar with your medical appointments and treatment schedule. Take these records with you to your visits. The more organized you are, the better able you will be to help manage your care.

Come prepared to appointments. Try to write down any questions ahead of time. Ask your doctor if you can send the list before your visit. Make your questions specific and brief, and prioritize them in order of importance. Make sure that a member of the medical team reads all of your questions, because they may see some that are more important than you realize.

You can get information from all members of your medical team, not just your doctor. Oncology nurses are very well informed about cancer treatments and are a good source of information on a wide range of topics. Oncology social workers are also available to assist with practical and emotional needs from the time of diagnosis and onwards.

Get help when you need it. Remember, you are your most important advocate. Your healthcare team is there to help you. Let them. If you are dealing with troubling side effects, it is better to seek advice rather than wait to see if the symptoms become worse. Don't wait for your next scheduled appointment to contact your medical team about an important issue.

GETTING THE MOST OUT OF YOUR APPOINTMENTS

At home

- Keep a journal of your symptoms to help you remember what you want to discuss with your doctor during your next office visit.
- Make a list of questions that you want to ask your doctor. If the questions are urgent, don't wait for your next visit; call the doctor's office to discuss your concerns.

At your next doctor's visit

- Bring your symptom journal and list of questions, and discuss them with your doctor or nurse.
- Ask a family member or friend to come with you to provide emotional support and take notes. They can think of questions you may not have thought to ask, and point out changes you may not have noticed. Check with the doctor before recording any conversations.
- Do not be afraid to ask questions if you do not understand something. If your doctor uses medical terms you don't understand, ask him or her to explain it in another way. If you understand better with pictures, ask to see x-rays or slides. Your doctor will want to know if you are uncertain or confused, and will explain things to you.

- Clarify who should be contacted for specific sorts of questions, or for weekend support.
- Ask if members of your medical team communicate by email.
- Before leaving the doctor's office, make sure that you understand the next steps in your care.
- Ask for written information that you can take home to help you remember what to do and learn more about your treatment.

Referral to a New Doctor or Getting a Second Opinion

Patients must be comfortable with their doctor and the approach that they take. If you are not comfortable, you should discuss your concerns. Confidence in your medical team often leads to confidence in treatment. If you do not feel that the team is a good match, you should ask your family doctor or specialist for a referral to another specialist.

Even if you have a good relationship with your doctor, you may want to seek a second or third opinion before beginning therapy. The purpose of the second opinion is to make sure that the suggested treatment plan is reasonable and the best choice for your particular case.

Most doctors understand the value of a second opinion when facing a major decision. It doesn't necessarily mean you have to change doctors. And, when you are able to talk with several experts about the disease, it can help you feel more confident knowing you have explored every possible resource to receive the best available care. You can discuss how to get a second opinion with your specialist or your family doctor.

If your doctor is recommending immediate treatment, ask if it would be okay to briefly delay the start of treatment to give you extra time to get a second opinion.



DIAGNOSIS

Understanding how CLL is diagnosed and what it means will help you make the best decisions about your treatment and wellbeing.

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Doctors need the results of various tests to determine if you have CLL. Getting a diagnosis can sometimes take a while.

It is important for your doctors to have as much information about your cancer as possible. This helps them to work out the stage of your cancer. The stage of the cancer will help your doctor decide which treatment is best for you.

At times, just about everyone will have to wait to have tests or to get the results. Many people begin to worry that the CLL will get worse during this time. CLL usually grows very slowly and this is not likely to happen.

It always helps to ask your doctor or nurse how long your test results will take. If you have not heard anything a couple of weeks after your test, call your doctor's office or clinic to check if your results are back.

Diagnostic Tests

You may have the following tests. Not all testing is required. Your medical team will determine what tests are needed.

A CLL diagnosis is usually made from blood cell counts and a blood smear examination. Usually blood is taken from the arm with a needle. The blood is collected in tubes and sent to a lab.

- **Complete blood count (CBC).** The CBC is a test that measures how many blood cells are in your blood. It measures how many red blood cells, white blood cells and platelets there are. The numbers of the different blood cells are often talked about as the 'counts'. A person with CLL will have a high number of lymphocytes. There may also be lower numbers of red blood cells, neutrophils and platelets.
- **Blood smear examination.** A sample of your blood will be examined under the microscope to determine whether CLL cells are present. Flow cytometry uses a machine that looks for certain substances on or in cells that help identify what types of cells they are (markers). CLL cells usually have a marker called CD5 that is normally found on T-cells, but not on normal B cells. For someone to have CLL there must be at least 5,000 of these cells (per mm³) in the blood.

A lymph node biopsy might be done to diagnose SLL. It involves the removal of a sample of tissue (cells), usually performed by a surgeon.

- **Lymph node biopsy.** For this test, a doctor removes some cells from your lymph node with a needle or removes the whole or part of a lymph node during a surgical procedure, so they can be looked at under a microscope. The method used to obtain your biopsy will depend on where your nodes are found and the preferred practice in your hospital.



Mary Jon,
patient

"Defer major decisions until you have had time to adjust to your diagnosis and understand your situation."

Other tests you might have at diagnosis or before starting treatment include the following:

- **Bone marrow tests.** Bone marrow tests are not usually needed to make a CLL diagnosis. They may be done before treatment starts.

Bone Marrow Test	Description
Bone marrow aspiration	A thin hollow needle is inserted into the bone (usually a bone in the back of the pelvis) and a small amount of liquid (marrow) from the bone is removed. Even with the numbing local anesthetic, this procedure can be painful for a few seconds while the marrow is withdrawn.
Bone marrow biopsy	The area is frozen and a slightly larger needle is inserted into the bone (usually the hip bone) to take out a small piece of bone and marrow. The procedure does not require any stitches.

- **Ultrasound.** Ultrasound imaging uses sound waves to produce pictures of the inside of the body.
- **CT (computed tomography) scan.** A CT scan is a series of detailed X-ray pictures that give a 3 dimensional (3D) picture of the body. This test can help find enlarged lymph nodes and abnormalities in other organs.

CAUTIONS ABOUT INTERPRETING LAB REPORTS

It is important to carefully review the findings of your laboratory test and imaging scans with your doctor.

Your blood tests must be looked at as a trend over time and not in isolation.

Tests can be reported as “normal” even though CLL may be present.

Tests may be reported as “abnormal” even though CLL is not present.

Other conditions may mimic CLL.

Often, follow-up tests are needed to clarify the results of tests.

Staging

CLL and SLL are staged based on the findings from your clinical examination. Knowing the stage of your CLL or SLL helps your doctor determine the extent of your disease and monitor its progression over time.

Most doctors in North America use a system called the Rai Staging system to stage CLL, either the classic or the modified version. There is another staging system called Binet Staging, which is used in Europe. Both systems classify CLL and assign risk categories based on the:

- Number of lymphocytes found in the blood
- Enlargement of the lymph nodes, liver and spleen
- Number of platelets found in the blood
- Number of red blood cells found in the blood

CLL STAGING – RAI STAGING SYSTEMS

Classic Rai (stage)	Modified Rai (risk level)	Signs and Symptoms
0	Low	<ul style="list-style-type: none"> • There are too many lymphocytes.* • The numbers of red blood cells and platelets are normal. • The lymph nodes and spleen are not enlarged.
1		<ul style="list-style-type: none"> • There are too many lymphocytes. • The numbers of red blood cells and platelets are normal. • The lymph nodes are enlarged, but the spleen is not.
2	Intermediate	<ul style="list-style-type: none"> • There are too many lymphocytes. • The numbers of red blood cells and platelets are normal. • The lymph nodes may be enlarged. The spleen is enlarged.

Classic Rai (stage)	Modified Rai (risk level)	Signs and Symptoms
3	High	<ul style="list-style-type: none"> • Too many lymphocytes in the blood • Lymph nodes, spleen or liver might be enlarged • Low number of red blood cells in the blood (anemia) • The number of platelets is normal
4	High	<ul style="list-style-type: none"> • Too many lymphocytes in the blood • Lymph nodes, spleen or liver might be enlarged • Low number of red blood cells in the blood (anemia) • Low number of platelet in the blood (thrombocytopenia)

* A high lymphocyte count is defined as more than 15,000 lymphocytes per cubic millimeter ($> 15,000/\text{mm}^3$)

Your doctor may also use the Ann Arbor Staging System for SLL.

The stage is determined by:

- The number and location of lymph nodes affected;
- Whether the affected lymph nodes are above, below or on both sides of the diaphragm (the large, dome-shaped muscle under the ribcage that separates the chest from the abdomen);
- Whether the disease has spread to the bone marrow or other organs.

There are four main stages:

- In stages I and II, the cancer is limited to one or two areas of the body (early stage). In stages III and IV, the cancer is more widespread (advanced stage).

SLL STAGING – ANN ARBOR STAGING SYSTEM

Stage	What It Means
I	Localized disease: one group of lymph nodes affected
II	Two or more groups of lymph nodes are affected but they are all in the chest or all in the abdomen
III	Two or more groups of lymph nodes are affected in both the chest and the abdomen with or without involvement of a nearby organ.
IV	Widespread disease: lymphoma is in multiple organs or tissues (e.g., bone marrow, liver or lungs) and may also be in the lymph nodes.

Your doctor may also add a single letter to the stage.

A generally means the patient has not experienced any troublesome symptoms.

B means the patient has experienced one or more of the following symptoms:

- Unexplained weight loss of more than 10% in the six months before diagnosis
- Unexplained, intermittent fevers with temperatures above 38°C (100.4°F)
- Drenching night sweats (requiring pajamas or bed sheets to be changed).

X if patients have a tumour in the chest that is at least one-third as wide as the chest, or if tumours in other areas are at least 10 cm (4 inches) wide. This is called **bulky disease**. Patients with bulky disease usually need more intensive treatment than patients without bulky disease.

Prognosis

Prognosis is the medical term used to describe how the disease will progress and the likelihood of recovery. It is often one of the first things that patients ask their doctor. A prognosis is usually based on information gathered from hundreds or thousands of other patients who have had the same disease. This information provides doctors with a general idea of what to expect when a patient is diagnosed with CLL. It also helps

guide them on the kind of treatments that have been most successful in treating CLL.

However, it is important to remember that no two patients are alike and that information from large groups of people does not always accurately predict what will happen to a particular patient.

Molecular Genetics Testing

Doctors may order more tests to find out what chromosome abnormalities and genetic changes are present in your CLL cells. The results of these tests may help doctors determine the best course of treatment. 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 genetics testing.

The **FISH** test (fluorescent in situ hybridization) looks for abnormalities in the cancer cell genes by making particular abnormalities in genes glow (fluoresce) so they are easier to see. FISH testing is important for determining prognosis and helps doctors to divide CLL into different risk groups. The FISH results may help determine which type of therapy is best for your cancer.

One type of chromosome abnormality is called a deletion, which happens when part of the chromosome is missing. Another type of chromosome abnormality is a trisomy, which indicates the presence of an extra copy of a chromosome.

The following table shows the chromosome changes and gene mutations most commonly found in CLL:

Chromosome or gene mutation	How often they occur in patients with CLL	Possible impact on a patient's outcome
12+ or trisomy 12	10% to 20%	Not known. Increased probability of a Richter's transformation.
Del(11q23)	5% to 20%	Might have poor outcome, but can be treated successfully with chemoimmunotherapy
Del(13q14)	51% to 62%	Good outcome if this is the only cytogenetic change
Del(17p)	3% to 7% of untreated patients	Poor outcome with chemoimmunotherapy; better response with targeted therapies

[Del means deletion of some of the genetic material. The numbers in parentheses (e.g., 11q23) indicate the chromosome and the area on the chromosome where the deletion is located.]

IgVH testing may also be done to see if the immunoglobulin heavy-chain variable-region (IgVH) gene in the cancer cells is mutated or unmutated. Research has shown patients with IgVH gene mutations usually have better outcomes.

Questions to Ask Your Doctor About Your Diagnosis

1. Do I have a slower or faster-growing form of CLL?
2. What is the stage of my disease?
3. Could the symptoms I'm experiencing be caused by CLL?
4. How long does it take for the disease to progress?
5. How can I take care of myself now that I have CLL?



TREATMENT

This section includes information to help you understand your treatment options, as well as a list of questions you may wish to ask your healthcare team.

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Many people with CLL do not require treatment right away and some people never require treatment for their CLL.

The decision to start treatment depends on whether you have signs or symptoms that are associated with progressive disease. Together, these signs and symptoms are called treatment indications. Treatment is started only if you have at least one of the treatment indications listed in the table below:

Treatment Indications for CLL

Evidence your bone marrow is unable to keep up with your body's need for healthy blood cells - measured by the development of, or worsening of, anemia (low red blood cell counts) and/or thrombocytopenia (low platelet counts).

Massive spleen, progressive spleen enlargement, or an enlarged spleen that is causing symptoms.

Massive lymph nodes (at least 10 cm in longest diameter), progressive lymph node enlargement or large lymph nodes that are causing symptoms.

Increase in number of lymphocytes of more than 50% over a 2-month period or lymphocyte doubling time (LDT) of less than 6 months.

Autoimmune anemia and/or thrombocytopenia (low numbers of red blood cells or platelets that results when your body makes antibodies that destroy them) that doesn't respond to standard medications.

'B' symptoms, defined as any one or more of the following disease-related symptoms or signs:

- Unintentional weight loss of 10% or more within the previous 6 months;
- Significant fatigue (inability to work or perform usual activities);
- Fevers higher than 38.0°C for 2 or more weeks without other evidence of infection; or
- Heavy night sweats for more than 1 month without evidence of infection.

Watch and Wait

If your CLL is slow growing and not causing you serious symptoms, you likely will not have treatment right away. This approach is called 'watch and wait' or 'watchful waiting' or 'active monitoring'.



Anonymous,
patient

"Find your own way to live with uncertainty. Live in the moment. Don't lose today worrying about tomorrow."

Watch and wait is a strategy where doctors monitor you closely, but do not treat you until symptoms appear or change. Watch and wait is the recommended care for those who do not meet any of the indications for treatment listed in the table above.

This does not mean your cancer is being ignored by your medical team. During the watch and wait period, you will meet regularly with your cancer specialist to monitor changes in your disease and overall health. At these appointments, your doctor will examine you and do blood tests. They will also ask how you are feeling and about any symptoms you have.

The results of exams and blood tests over time will help your doctor determine if you need treatment and the type of treatment you should have.

Understandably, many people worry their CLL will get worse if they don't have treatment. It is natural to want treatment if you have cancer. Studies comparing watch and wait with early treatment have shown there is no benefit to early treatment for patients with asymptomatic CLL. Furthermore, some patients will never need treatment for their CLL. And with watch and wait, you can avoid the side effects of treatment until it is needed.

Treatments for Progressive/Symptomatic CLL

Treatment is usually only started if the CLL progresses and results in the development of disease related symptoms. Although no cure has been found yet for CLL, there are many treatment options that allow patients to feel well and live for years in good health.

The goals of treatment are to:

- Reduce the numbers of CLL cells in your blood, lymph nodes, spleen and bone marrow
- Relieve your symptoms and maximize your quality of life for as long as possible

The type of treatment you have will depend on a number of factors, including:

- Your age
- Your general health or fitness
- Any other illnesses you have
- What changes have happened to the genes and chromosomes of the CLL cells

Your doctors will take all these factors into account when planning your treatment.

The following chart provides an overview of the treatment options and possible outcomes for CLL. The sequence of treatment in CLL is important because, in some cases, the first treatment you get may affect your next treatment (if it becomes necessary). Please talk to your doctor about what may come next in your treatment. You should be aware of possible future therapies and discuss them with your doctor early on in your treatment journey.

HOW WILL MY CLL BE TREATED?

Watch and Wait

How long until I get treatment?

If signs or symptoms of progressive disease never appear, treatment may never be needed

Treatment will begin when signs or symptoms of progressive disease appear

Primary (First-line) Therapy

What will my treatment be?

Chemotherapy (with or without antibody therapy)

Targeted drug

Radiation therapy or splenectomy

Clinical trial

WHAT HAPPENS AFTER TREATMENT?

Response to treatment

Remission

Regular follow-up visits with oncologist

Relapse

No response to treatment

Additional therapy

Before Starting Treatment

Before treatment starts, be sure to tell your medical team about any medicines, vitamins, herbs or different healing approaches that you may be using.

You may wish to consider obtaining an advanced directive before starting treatment. Advance directives are legal documents that describe what you want for your future medical care, in the event that you become physically or mentally unable to speak for yourself. They take effect only if you become unable to make your own decisions. There are two types of advance directives: a living will, which is a set of written instructions about your wishes for your medical care; and a power of attorney, where you choose someone you trust to make your healthcare and financial decisions for you. If you need advice about creating these documents, please ask a doctor, social worker or lawyer.

What to Expect During Treatment

Each patient responds differently to treatment. It is important to understand what to expect with your treatment, possible side effects, and any effects on quality of life, such as lifestyle, emotions and financial issues.

Doctors talk about results of treatment using certain terms that you may want to become familiar with. They include:

- **Primary therapy:** Also called front-line or first-line therapy. This is the first treatment given after a cancer diagnosis. If a patient requires more treatment, subsequent treatment may be referred to as second-line, third-line, etc.

- **Complete response:** A term which means that all signs of the cancer have disappeared following treatment. This does not mean the cancer is cured but it is undetectable using current laboratory testing.
- **Partial response:** Also called partial remission. The term used when a cancer has decreased in size by half or more but has not been completely eliminated. The cancer is still detectable and more treatment may be necessary.
- **Minimal Residual Disease (MRD):** The term used when a minute number of cancer cells remain either during or after treatment.
- **Stable disease:** The term used when the cancer does not get better or worse following treatment.
- **Refractory disease:** A cancer that does not respond to treatment or that relapses very soon after treatment is completed (for example within 6 to 12 months).
- **Relapse:** The return of cancer after a period of improvement.

Types of Treatment

If you require treatment for your CLL, your doctor may recommend one or more of the types of treatment listed below:

- **Drug therapy**
 - Chemotherapy
 - Antibody therapy
 - Other targeted therapy
- **Radiation therapy**
- **Surgery**
- **Stem cell transplantation**
- **Supportive care**

Drug Therapy

Powerful anticancer drugs may be used in your treatment.

Drug therapy may be used to:

- prevent the cancer spreading
- slow the growth of the cancer or kill cancerous cells
- relieve symptoms.

Before your treatment starts, you will be given information about what to expect from the treatment you will have and how to take care of yourself during treatment.

Make sure you get patient data sheets for each of the drugs you will receive. These sheets explain what the drugs are, what their side effects are and which side effects require immediate treatment.

Side Effects

Many people are frightened by the side effects of drugs. However, it is important to understand that:

- Not all patients who receive drug therapy experience side effects;
- Side effects are not always severe, they can be mild;
- Different drugs have different side effects;
- There are many effective treatments that can reduce side effects or prevent them from happening altogether.

Everyone reacts to drug therapy differently. Even people of similar age and health can experience different side effects from treatment.

Most side effects are short-lived, but some can last for a few weeks or months after treatment has finished. Occasionally, side effects can be permanent. Some side effects can start long after treatment has finished. These are called late-effects. Your doctor will talk to you about any effects before you start treatment.

Depending on the side effects you experience from drug therapy and how strongly you feel them, you might not be able to maintain your usual level of activity during treatment. You might need to set aside more time for rest and healing.

DID YOU KNOW?

Not all drugs that are approved by Health Canada are publicly funded. Each province and territory has their own publicly funded prescription drug program. The drug coverage provided by each province can vary a lot, and each province decides who is eligible for each type of coverage.

Who Pays for Drugs in Canada?

Once a drug is approved for use in Canada, there are two ways patients can have their medicines and treatments paid for:

- 1. Public Insurance:** provided through provincial and territorial governments.
- 2. Private Insurance:** provided through employers or purchased individually.

Patients also have the option to pay for the drug themselves. In certain circumstances, programs are available to help a patient pay for the costs of drugs, if they meet criteria.

Since there are some medications that are only funded through private insurance plans, it's very important to tell your doctor if you have private insurance. Ask your doctor if your treatment is covered by public health insurance, and find out what other treatment options exist if you have private insurance.

Chemotherapy

Chemotherapy is a type of treatment that includes a drug or combination of drugs to kill cancer cells. A combination of drugs may be prescribed to improve the chances for success as each drug kills the cancer in a different way. If chemotherapy is given in combination with antibody therapy it is called chemoimmunotherapy.

Chemotherapy works to prevent the cancerous cells from multiplying and to remove or reduce the number of cancerous cells in the body.

How chemotherapy works

Chemotherapy is a systemic therapy, which means it affects the whole body. Chemotherapy targets and kills cells that grow and divide quickly, such as cancer cells. Because of how they work, chemotherapy drugs can also have the same effect on normal cells that divide quickly, like hair, nails, and the cells in your mouth and digestive tract. This is why chemotherapy can cause side effects including hair loss, diarrhea, nausea and vomiting.

Cancer is often described as being either chemosensitive or chemoresistant.

- **Camosensitive** means that the cancer is responding to chemotherapy and the chemotherapy treatment is effective in killing the cancer cells.
- **Chemoresistant** means that the cancer does not respond to chemotherapy and an alternate treatment is required. If this happens, another drug therapy is usually offered.

How chemotherapy is given

Each dose of chemotherapy kills only a percentage of cancer cells. For this reason, chemotherapy is often given in multiple doses in order to destroy as many cancer cells as possible.

Chemotherapy treatment is usually followed by a period of rest and recovery. Together, each period of treatment and non-treatment is called a chemotherapy cycle. Chemotherapy drugs may be given once per cycle or on multiple days per cycle, depending on your treatment plan. The full course of chemotherapy (the total number of cycles) may take several months.

A typical treatment session will involve having blood tests and a visit with your oncologist or nurse, followed by your chemotherapy.

Some drugs are given by mouth as capsules or pills. Other drugs are given by needle directly into a vein (intravenous or IV infusion).

If you are going to receive intravenous drugs, your doctor might recommend having a venous catheter inserted. A venous catheter (a small, flexible plastic tube) is a device that is put into a vein to make it easier to give medication. There are different types but each device works in the same way. The one chosen for you will depend on the normal practices at your hospital.

Type of Venous Catheter	Description
PICC line	A peripherally-inserted central catheter (PICC) is a catheter inserted into a vein in the arm. The catheter is pushed up the vein until the end reaches the major vein leading to the heart. It can be used to deliver drugs or withdraw blood samples.
Implanted chemotherapy port (port-a-cath)	This device is a small round chamber with a catheter placed under the skin, usually in the chest. The catheter is connected to the major vein leading to the heart.

Common side effects of chemotherapy

Chemotherapy does often cause side effects, though the severity varies person-by-person and by type of drug. Medications to prevent side effects may be given prior to, alongside or after chemotherapy treatment. Potential side effects from chemotherapy include:

Decreased Blood Cell Production: Blood cells, including red blood cells, white blood cells and platelets, are continually being produced in the bone marrow. Because these cells are always dividing, they are also targeted by chemotherapy, so the number of all blood cells can be reduced. This is called myelosuppression.

It is important to be aware of the symptoms of myelosuppression.
If you notice these symptoms, tell your doctor immediately.

Type of Myelosuppression	Possible signs and symptoms	What can be done?
Anemia – decrease in the number of red blood cells	<ul style="list-style-type: none"> Feeling tired and weak Shortness of breath Lightheadedness 	<ul style="list-style-type: none"> Injections may be given to help boost the bone marrow production of red blood cells Red blood cell transfusions might be required for severe anemia
Neutropenia – decrease in the number of neutrophils, a type of white blood cell that fights infections	<ul style="list-style-type: none"> More frequent and/or serious infections or the recurrence of old viruses, like shingles Fever; sore throat; rash; diarrhea; redness, pain or swelling around a wound 	<ul style="list-style-type: none"> Chemotherapy might be delayed or the dose reduced Antibiotics may be prescribed Injections might be given to boost the bone marrow production of neutrophils (G-CSF)

Thrombocytopenia – decrease in the number of platelets

- Increased bruising
- Excessive bleeding from cuts, nosebleeds and bleeding gums
- Avoiding blood-thinning medications, such as aspirin, might be recommended
- Platelet transfusion might be necessary in severe cases

Nausea and vomiting

Diarrhea

Fatigue: Severe fatigue can be a symptom of anemia and should be mentioned to your doctor.

Chemo brain: Various treatments may impair your cognitive function which can lead to something known as “chemo-brain”, “brain fog”, or “cancer-related cognitive disorder”. You may notice difficulties concentrating or paying attention, remembering new things, recalling old memories or saying the right words. For most patients, these symptoms will get better in the months following the completion of treatment. If you continue to experience these symptoms, discuss them with your doctor.

Changes in taste: Chemotherapy can often alter the taste of foods. Familiar foods can taste different (called dysgeusia) or food flavours can taste less intense than normal (hypogeusia). Taste changes are usually temporary and disappear once your chemotherapy treatment is finished.

Loss of appetite

Sexual Issues: For women, chemotherapy may leave you with temporary or permanent damage to your ovaries leading to hormonal changes or menopausal changes. This may cause hot flashes, vaginal tightness, and vaginal dryness. Ask your doctor about treatment options. For men, chemotherapy may lower your testosterone levels and/or damage blood flow to the penis, resulting in various sexual concerns such as the inability to keep a firm erection (also known as erectile dysfunction), penile pain, or difficulty reaching orgasm. Many men find it difficult to discuss their sexual concerns with others; however, your doctor, or a specialist in sexual health, can help you overcome these issues. It is also important that partners practice safe sex and use a condom during treatment to ensure none of the chemotherapy chemicals are passed to your partner.

Antibody Therapy

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.

CLL cells have proteins on their surface too and antibodies can be made in a laboratory to recognize these proteins. The man-made antibody sticks to the target protein on the CLL cell. This marks the cell so that the immune system will kill the cell. Antibody therapy is sometimes known as 'immunotherapy' because the medical name for an antibody is 'immunoglobulin'. Several antibody therapies are available for the treatment of CLL and many more are under clinical investigation.

Antibody therapy is most often given in combination with chemotherapy drugs, which is called chemoimmunotherapy. Like some chemotherapy drugs, antibody therapies are given by needle directly into a vein (IV infusion) or under the skin (subcutaneous).

Common side effects of antibody therapy

Antibody therapies can cause some side effects. In general, the side effects are milder than the side effects of chemotherapy. Most of the side effects from antibody therapy are minor and short-lived, lasting only during the actual treatment and for a few hours afterwards (often referred to as 'infusion related reactions'). The chances of experiencing infusion related reactions decrease with each treatment received because the patient adjusts to the treatment and, as treatment continues, there are fewer lymphoma cells to kill.

Sometimes, patients will experience an allergic reaction to the antibody therapy at the time of infusion. Patients are monitored closely during their treatment sessions for signs of allergic reaction, including itching, rash, wheezing and swelling. If these symptoms occur, the treatment is slowed down or stopped for a short time until the symptoms go away. Medications (antihistamines and acetaminophen) are commonly given before treatment to avoid allergic reactions.

The most common side effect is:

- Flu-like symptoms (fever, chills, sweating)

Less common side effects include:

- Nausea
- Vomiting
- Shortness of breath
- Low blood pressure
- Fatigue
- Headache
- Infection

Other Targeted Therapies

Scientists are learning more about the cell signals (the communication of information within the cell and between cells) that contribute to the growth and survival of CLL cells. Drugs are being developed to specifically block these signals and stop the growth and spread of CLL cells, while limiting damage to healthy cells.

Currently, there are many new targeted therapies undergoing investigation in clinical trials and some have recently been approved to treat CLL.

Many of these targeted therapies are available in pill form, making it possible for patients to take their medication at home.

Most targeted therapies affect the bone marrow so there is a risk of infection and bleeding. Many patients experience fatigue and the drugs can cause nausea or bowel upset. Some of these drugs can also cause peripheral neuropathy (see description under chemotherapy side effects).

Radiation Therapy

Radiation therapy is rarely used to treat CLL and not often used to treat SLL. This treatment is sometimes used to treat an enlarged (swollen) lymph node, spleen or other organ that is blocking the function of a neighbouring body part.

Radiation therapy uses high-energy X-rays, like those used to take pictures, to kill cancer cells. The X-rays cause damage to the cell's DNA (the genetic material of the cell) which makes it impossible for the cancer cell to repair itself, so the cell dies.

Radiation does not only affect cancer cells. Healthy cells in the area will be killed off as well. Care is always taken to plan the treatment properly and ensure that other areas of the body are affected as little as possible. Healthy areas are shielded from the radiation with lead shields similar to the ones you wear at the dentist when receiving an X-ray. Lead blocks the path of any stray radiation beams and prevents them from affecting normal cells.

Splenectomy

The spleen is an organ on the left side of the body, near the stomach. A splenectomy is an operation to remove the spleen. It can be helpful if the spleen becomes very large as a result of the disease. CLL cells can enlarge the spleen and cause discomfort in some patients. Also, an enlarged spleen may lower your blood cell counts to dangerous levels.

Stem Cell Transplantation

Hematopoietic stem cells are a group of cells which are immature and can grow and change into any type of cell found in the blood - red blood cells, white blood cells or platelets.

Hematopoietic stem cells can be found in the bone marrow (the spongy material inside the large bones of the body that is responsible for blood cell production), circulating blood (also called peripheral blood) and umbilical cords.

Stem cells, because they divide rapidly, can be killed off by chemotherapy and radiation therapy. Therefore, the doses of chemotherapy and radiation therapy used to treat lymphoma are limited due to the risk of damaging these stem cells. Patients with lymphoma that is difficult to treat or resistant to standard therapy may benefit from chemotherapy or radiation therapy given in very high doses (myeloablative therapy). However, this can potentially destroy all stem-cells and leave the patient at very high risk for infection.

To combat this problem, the patient receives an infusion of stem cells, which is commonly called a transplant. After myeloablative therapy, they will receive stem cells from a compatible donor (allogeneic transplant) to replenish those destroyed by high dose chemotherapy.

Allogeneic stem cell transplantation is helpful for some patients with CLL. Stem cell transplants are usually done as part of a clinical trial in younger patients with high-risk genetic changes or relapsed/refractory disease (disease that does not respond to treatment or returns after treatment).

If your doctor feels that it is possible you may eventually need a transplant, they will discuss it with you during your treatment planning.

Supportive Therapy

Supportive therapies are often given to prevent or treat CLL symptoms and/or treatment side effects.

Supportive care for CLL can include:

- Antibiotics to treat infections caused by bacteria or fungi.
- Antivirals to treat infections caused by viruses.
- Vaccinations.
- Blood transfusions or growth factors to increase red blood cell counts.
- IVIG treatments may be used to help boost your immune system.
- Growth factors to increase white blood cell counts or boost immunoglobulin levels.

Questions to Ask About Treatment

General Questions

1. What are my treatment choices? Which do you recommend for me? Why?
2. What are the names of the drugs I will be given? What are they for and what will each one do?
3. How will we know if the treatment is working?
4. What are the chances that the treatment will be successful?
5. How will treatment affect my life? My work? My family?
6. Are new treatments being studied? Would a clinical trial be appropriate for me?
7. Who will manage my treatment program?
8. Where can I go for more information?

Practicalities of Treatment

1. How often will I need to come in for treatment or tests?
2. What if I miss a treatment?
3. How long will my treatments last?
4. Are there any special foods I should or should not eat?
5. Can I drink alcoholic beverages?
6. Should I still take the other drugs I am on?

7. If I do not feel sick, does that mean the treatment is not working?
8. Is it okay to continue with the supplements I am currently taking?
9. What costs will I encounter? What should I do if I can't afford it?
10. Who should I call if I have questions? What is the best time to call?
11. What should I do to try to stay healthy and strong during my treatment?
12. Can I come for my treatments alone or do I need assistance?

Side Effects of Treatment

1. What are the possible risks or side effects of treatment? How serious are they?
2. Can the side effects be managed?
3. What symptoms or problems should I be on the lookout for? What should I report right away?
4. How long will the effects of treatment last?

"Listen to your body, if it wants to sleep, let it sleep, don't force yourself to stay awake to get a task/job done."

Eric,
patient



RELAPSED OR REFRACTORY CLL

Most patients undergoing treatment for CLL will have a partial or complete response to their treatment. If the disease returns or doesn't respond to the initial treatment, more treatment may be necessary.

RELAPSED OR REFRACTORY CLL

Relapsed CLL means that the disease has returned after responding to treatment.

This is sometimes also called a recurrence. Refractory CLL means that your disease does not respond to a specific treatment or that the response to the treatment does not last very long.

There are many treatment options for people with relapsed or refractory CLL. The type of treatment that you will receive if you need additional treatment depends on factors such as age, extent and location of the disease, overall health, types of previous therapies you received, and the length of response to previous therapies.

Many of the new therapies most recently approved by Health Canada and those being tested in clinical trials are used specifically for patients with relapsed or refractory disease. CLL research is evolving quickly as doctors and scientists discover new treatments and more effective ways of giving existing therapies.



CLINICAL TRIALS

Clinical trials are research studies that involve people. Understanding what they are can help you decide if a clinical trial might be an option for you.

Research is constantly underway to develop new treatments and to improve existing ones.

A major part of developing new treatments involves clinical trials – carefully planned research studies that are conducted with patients in order to test new medications or new treatment approaches. The new treatment is usually compared with an existing treatment to determine if the outcome is more beneficial for patients.

A clinical trial can test many aspects of treatment, including the safety and effectiveness of new medications, the addition of new medications to standard treatments and potential new methods of administering standard treatments.

The protocol of a clinical trial is examined and approved by ethics committees and must meet rigorous government and medical standards. A significant amount of careful, detailed research is conducted on the new medication before it reaches the stage where it is tested on patients.

There are different types of trials in which a patient may participate. They are listed in the following table:

Trial Type	Major Differences
Phase I	<ul style="list-style-type: none">• Tests for safety and appropriate dose of a new treatment (does not compare it with another treatment)• Increased risk of side effects• Usually includes only a small number of patients who often have advanced disease that has not responded to current treatments
Phase II	<ul style="list-style-type: none">• Tests for side effects and efficacy of new treatment (does not compare it with another treatment)• Larger number of patients than a phase I trial
Phase III	<ul style="list-style-type: none">• Further tests the new treatment on large numbers of patients once the phase II trial has shown the treatment to be effective and safe• The new treatment is compared with a standard treatment to determine if the outcome is more beneficial for patients (randomized controlled trial)
Phase IV	<ul style="list-style-type: none">• Further study of the treatment after the treatment has been licensed for use in standard practice

Patients who choose to take part in a clinical trial must give informed consent. This means that they are aware of the potential benefits and associated risks and that they are a willing participant. No patient should feel pressured to participate in a clinical trial. Furthermore, once a patient is in a trial they have the right to leave the trial at any time without explanation. Leaving a trial will in no way affect the attitude of your medical team, and you will still receive the best current standard treatments.

To learn more about clinical trials currently available in Canada and around the world, please visit www.lymphoma.ca/clinicaltrials



FOLLOW-UP CARE

Follow-up care after treatment is an important part of cancer care. Follow-up for CLL is often shared among cancer specialists and your family doctor. Your healthcare team will work with you to decide on follow-up care to meet your needs.

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CLL can be treated very successfully, but it can take some time to recover from treatment.

Some side effects can take weeks or even longer to go away. You might feel tired for many months or find you pick up infections more easily. Adjusting to the “new” normal routines of life after treatment can take a few weeks or months.

Ask your doctor or nurse about what to expect. Keep track of ongoing side effects or other health problems. Ask about any possible late side effects and when these might happen. Your care after treatment will depend, to a large extent, on what type of treatment you received, and how you responded to treatment.

Follow-up Appointments

Once you have completed active treatment, you will likely be given a follow-up care plan to monitor your progress and recovery as well as to watch for a potential recurrence. It is very important to go to all of your follow-up appointments. Your schedule of visits and the tests and procedures that you will undergo during follow-up are tailored to your individual situation.

Your follow-up appointment may include any combination of the following:

- **Physical exam**
- **Blood tests:** to assess your status and evaluate the need for additional treatments
- **Imaging tests:** such as CT, PET, or other imaging scans to measure the size of any remaining tumour masses if internal lymph nodes or other internal organs are or were affected.

Your doctor will also tell you to watch for specific signs or symptoms of recurrence. Having ongoing or new symptoms can be alarming for people who have been through cancer. The fear of recurrence is real and commonly experienced by patients. There are a number of ways that you can deal with this fear. Remember that even though new symptoms may be concerning, not all issues that arise will be cancer-related. However, it is still important to bring anything that concerns you to the attention of your medical team – don't ignore them. Let your healthcare team know about them right away – you do not have to wait until your next scheduled appointment.

Furthermore, almost all cancer treatments have side effects. Some may last for a few weeks to months, but others can last the rest of your life. Use the time during your follow-up appointments to talk to your medical team about any changes or problems you notice and any questions or concerns you have about your health after treatment.

Notes from your previous clinic visits should automatically be sent to your family doctor, but you may wish to check with your cancer medical team

to make sure this happened. Do not be afraid to be an advocate for your care and facilitate the process of ensuring that all of your records have been sent to your family doctor.

It is very important that your family doctor is and continues to be up-to-date on the following:

- All medications that you are currently taking (including over-the-counter medicines such as pain relievers, laxatives, nutritional supplements, vitamins, minerals and herbal therapies)
- All of the specialists you are still seeing and why
- All your future screening tests and how often these should be scheduled
- Your feelings, fears or concerns about anything that may affect your recovery including symptoms or changes that you are experiencing that cause you to worry
- Any lifestyle changes you make, such as quitting smoking or changing your diet or exercise routine

In addition, you may start to see new or additional doctors such as a dentist, neurologist, physiotherapist or naturopath for other health-related issues. Keep in mind that if you change doctors, have a new doctor or are under the care of several different doctors, you may be the only one who has your complete health history. For this reason, it is important to keep up-to-date records of all the medical care you receive for lymphoma and other conditions because future decisions about your care may depend on what treatment you received in the past.

As part of life after diagnosis and potential treatment, there is a realization that life may never return to the normal that you were accustomed to before you were diagnosed. You are now faced with creating a new normal for yourself.

Part of this process involves re-evaluating personal relationships and professional and financial goals. For help with this process, please visit www.lifebeyondlymphoma.ca

Secondary Cancers

A secondary cancer is a new cancer, which is different from the CLL you were initially treated for, which develops after treatment for CLL. It may develop as a late effect of your initial treatments, such as chemotherapy and radiation.

CLL patients are at a higher risk of developing other kinds of cancer. The most common second cancer among CLL patients is non-melanoma skin cancer, followed by cancers of the digestive organs, prostate, breast and lung. You may also develop another type of blood cancer like myelodysplastic syndromes (MDS) or acute myeloid leukemia (AML). Therefore it is very important to remain vigilant and attend all of your required follow-up appointments to get the best care and surveillance during and after CLL treatment. It is also recommended to see a dermatologist once a year, use sun screen to reduce exposure to UV light, avoid tanning beds, quit smoking if you are a smoker and undergo regular screening for breast, prostate and colorectal cancer.

Richter's Syndrome (RS), also known as Richter's Transformation, is a rare complication of CLL characterized by the sudden transformation of the CLL into a significantly more aggressive form of large cell lymphoma.

Richter's Syndrome occurs in approximately 2-10% of all CLL patients during the course of their disease. In the most cases the normally slow growing, or indolent, CLL transforms into a common type of non-Hodgkin lymphoma (NHL) known as Diffuse Large B-Cell Lymphoma (DLBCL). Rarer cases transform into Hodgkin lymphoma (HL), and some types of T-cell lymphomas also have been reported.



MEDICAL TERMS

Absolute neutrophil count (ANC): The number of mature neutrophils in the bloodstream.

Acute: Sudden onset of disease or symptoms.

Advanced disease: Disease that has spread from the original site, often to multiple locations.

Allogeneic stem cell transplant: A procedure where a patient receives stem cells from the bone marrow or peripheral blood of a compatible donor. For additional information, see page 66.

Alopecia: Loss of hair, either from the head or elsewhere on the body. Alopecia during cancer treatment most commonly occurs as a side effect of chemotherapy and is almost always temporary. Hair will re-grow once treatment is finished.

Anemia: A condition where the number of red blood cells is below the normal range. The most common symptoms associated with anemia include fatigue, weakness and shortness of breath.

Ann Arbor Staging System: Describes the extent to which lymphoma has spread within the body. There are four main stages: I, II, III & IV. For additional information, see page 37.

Antibody: A protein that attaches to the surface of bacteria, toxins or viruses so they can be identified and destroyed by the immune system. For additional information, see page 62.

Antibody therapy: Laboratory-made antibodies attach to the target protein on the cancer cell, marking the cell so that the immune system will kill it. Antibody therapy is sometimes known as 'immunotherapy' or 'biologic therapy'.

Antiemetic: A medication that reduces or prevents nausea and vomiting.

Antigen: A molecule that causes the immune system to produce antibodies against it.

Antinauseant: A medication that prevents nausea.

Antipyretic: A medication that reduces fever.

Apheresis: A process in which the blood is passed through a machine that separates out one particular part or type of cell and returns the remainder to the circulation.

Autologous stem cell transplant: A type of bone marrow or stem-cell transplant where the patient receives their own cells instead of those from a donor.

Axilla (axillary): Refers to the area under the arm (armpit).

B cell: Also called a B lymphocyte, a B cell is a type of white blood cell that helps fight disease in the body.

B symptom: Symptoms that some people experience with CLL. B symptoms include fever, night sweats and weight loss. They are often associated with more advanced disease.

Benign tumour: A tumour that is not cancerous. Benign tumours can grow large enough to impact surrounding tissues.

Binet staging system: Describes the extent to which a cancer has spread within the body. There are three stages in the Binet staging system typically used with CLL in Europe: stage A; stage B; stage C (more widespread).

Biologic therapy: Treatments that stimulate the patient's immune system to fight infection or disease. Also called immunotherapy.

Biomarkers: Any substance found in an increased amount in the blood, other body fluids or tissues that can be used to indicate the presence of some types of cancer or predict the outcome of the cancer.

Biopsy: Removal of a small piece of tissue for examination under a microscope.

Blood cell: A general term that describes the three major cell types that circulate in the blood: red blood cells, white blood cells and platelets.

Bone marrow: The material inside the large bones of the body that produces red blood cells, some white blood cells and platelets. The bone marrow contains immature forms of these cells, called stem cells, which can be harvested for transplant.

Bone marrow aspiration and biopsy: A test routinely done to determine whether the cancer has invaded the bone marrow. In both tests a needle is inserted into the bone to remove a sample of the marrow. For additional information, see page 33.

Bone marrow transplant: See stem cell transplant.

Bulky disease: When CLL infiltrates the lymph nodes and other organs, such as the spleen. Patients with bulky disease usually need more intensive treatment than patients without bulky disease.

Cancer: Uncontrolled growth of abnormal cells.

Carcinogen: A substance that is known to cause cancer.

Catheter: A device, usually a flexible tube, which is used to give medications through a vein or take fluids (e.g., urine) out of the body.

Cell: The building block of all living tissues, it is the most basic functional unit in the body.

Central line: An intravenous catheter that is inserted into a large vein, usually in the neck or near the heart. It is used to administer medication or withdraw blood.

Cerebrospinal fluid: Watery fluid that surrounds the brain and spinal cord. It may be examined to determine if the cancer has spread to these areas.

Chemoresistant: A term used to describe cancer that does not respond to chemotherapy.

Chemosensitive: A term used to describe cancer that responds to chemotherapy.

Chemotherapy: Treatment with drugs that targets and kills cells that grow and divide quickly, such as cancer cells. For additional information, see page 56.

Chemotherapy cycle: A cycle includes each period of treatment and the non-treatment period of rest and recovery afterwards. Chemotherapy for CLL usually requires multiple cycles.

Chronic: A disease that lasts for a long period of time or is recurring.

Clinical trial: A research study involving patients performed under strictly controlled conditions to evaluate a new treatment. The ultimate goal is to find the most effective, least toxic treatment for a specific disease.

Combination chemotherapy: The use of a number of drugs together to treat cancer. Each drug kills the cancer in a different way, so a combination of chemotherapy drugs can be more effective than a single drug in destroying the cancer.

Complete blood count (CBC): A routine blood test used to determine the number of blood cells (red blood cells, white blood cells and platelets) in the bloodstream. A CBC is commonly done during a normal check-up with a doctor, and is often done during cancer treatment to monitor blood cell levels.

Complete response: Also called complete remission, it means that all signs of the cancer have disappeared following treatment.

CT scan or CAT scan: CT stands for computed tomography and CAT stands for computerized axial tomography. Both tests are a series of X-rays that provide detailed, three-dimensional images of the inside of the body.

Debulking: Treating cancer to reduce the size of the tumour. Debulking is usually achieved via surgery or radiation.

Deletion: Chromosome abnormality where part of the chromosome is missing. For additional information, see page 39.

Diaphragm: The thin, dome-shaped muscle below the heart and lungs that separates the chest from the abdomen.

Disease progression: A term used to describe a worsening of the disease despite treatment. The term is often used interchangeably with treatment failure.

DNA (deoxyribonucleic acid): The building block for all genetic material. It is a molecule inside cells that carries genetic information.

Drug resistance: Occurs when cancer cells do not respond to drug therapy.

Durable remission: The term used to describe cancer that has been in remission for many years.

Dysgeusia: An altered sense of taste.

Dysphagia: Difficulty in swallowing.

Echocardiogram: An imaging technique where an ultrasound machine is used to visualize the heart. Some chemotherapy medications can affect the heart and as such, cancer patients may require an echocardiogram.

Edema: Swelling caused by excessive amounts of body fluid.

Erythrocyte: Red blood cell.

Etiology: The cause(s) of disease. The cause of CLL and SLL is not known.

Extranodal disease: A term describing CLL that has spread to tissues outside of the lymphatic system.

Fatigue: Excessive tiredness and lack of energy, with a decreased capacity for daily activities.

Febrile neutropenia: Neutropenia (low white blood cell count) accompanied by fever and other signs of infection, is known as febrile neutropenia. If left untreated, febrile neutropenia can lead to serious infections, which may be life threatening and/or cause you to stay in the hospital.

FISH test: FISH stands for fluorescent in situ hybridization. This test looks for abnormalities in the cancer cell genes by making particular abnormalities in genes glow (fluoresce) so they are easier to see. For additional information, see page 39.

First-line or front-line therapy: See primary therapy.

Flow cytometry: A procedure that examines the molecular characteristics of cells.

Genes: Made up of DNA and found in all cells, genes contain the information to determine an individual's unique characteristics.

Gene therapy: The introduction of DNA into a patient to treat a disease. The new DNA usually contains a functioning gene to correct the effects of a disease-causing mutation.

Genetic mutation: A permanent change to the normal sequence of a gene. Genetic mutations may cause certain cancers.

Graft-versus-host-disease (GVHD): A complication that can occur after a patient has received a bone marrow or stem-cell transplant from a donor (an allogeneic transplant). The immune cells from the donor (the graft) attack the patient's organs and tissues, impairing their ability to function, and increasing the patient's risk of infection.

Hematologist: Doctor specializing in diseases of the blood.

Hemoglobin: A protein in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide from the tissues back to the lungs.

High-grade NHL: An aggressive, fast-growing form of NHL.

Hyperkalemia: High blood potassium.

Hyperphosphatemia: High blood phosphorus.

Hyperuricemia: High blood uric acid.

Hypocalcemia: Low blood calcium.

Hypogeusia: A loss of the sense of taste.

IgVH testing: Tests to see if the immunoglobulin heavy-chain variable-region (IgVH) gene in the cancer cells is mutated or unmutated.

Immune system: The body's defense system against infection and disease.

Immunoglobulin: Also called an antibody, it is any protein that is used by the immune system to identify and neutralize harmful agents, such as bacteria and viruses.

Immunosuppression: Suppression of the immune system due to the side effects of medications.

Immunotherapy: Treatments that stimulate the patient's immune system to fight infection or disease. Also called antibody therapy or biologic therapy. For additional information, see page 62.

Indolent lymphoma: A slow-growing form of lymphoma. Indolent lymphoma and low-grade lymphoma are terms often used interchangeably.

Intravenous (IV): Administered into a vein.

IVIG: Intravenous immunoglobulin (IVIG) is a blood product used to treat patients that have an increased risk of infection due to antibody deficiencies.

Lactate dehydrogenase (LDH): An enzyme found in the blood that indicates damage to cells. If elevated, it may indicate a more aggressive form of CLL.

Leukapheresis: A laboratory procedure in which white blood cells are separated from a sample of blood.

Leukemia: A cancer of white blood cells. In leukemia, the cancerous cells are in the blood, whereas in lymphoma the cancerous cells (lymphocytes) are primarily found in the lymphatic system.

Leukopenia: A low level of white blood cells. Since white blood cells are the main cells of the immune system, low levels leave a person at increased risk of infection.

Localized disease: Cancer that is contained to a small area of the body.

Low-grade lymphoma: Also referred to as indolent lymphoma, low-grade indicates a slow-growing lymphoma.

Lymph (lymphatic fluid): The watery fluid contained in lymphatic vessels. Lymph circulates lymphocytes throughout the lymphatic system.

Lymph nodes: Small, bean-shaped organs that contain lymphocytes. Lymph nodes filter the lymphatic fluid and remove any foreign invaders. There are hundreds of lymph nodes throughout the body. The major

lymph node clusters are found in the neck, under the arms, and in the chest, abdomen and groin.

Lymph node biopsy: Either a section of a lymph node or the entire lymph node is removed (by a surgeon) for examination under a microscope.

Lymphadenopathy: Swelling or enlargement of the lymph nodes due to infection or cancer.

Lymphatics: Lymphatic vessels and channels that carry lymphatic fluid and lymphocytes throughout the body.

Lymphatic system: The network of lymphatic vessels, lymph nodes and other organs that transport lymphocytes throughout the body to fight infection and disease. The lymphatic system also regulates fluid in the body. For additional information, see page 8.

Lymphoblast: An immature lymphocyte (B-cell or T-cell).

Lymphocytes: A type of white blood cell found in the lymphatic system and the bloodstream. Lymphocytes fight infection and disease and are an important part of the immune system.

Lymphocytosis: An increase in the number of lymphocytes in the blood.

Lymphoma: Cancer of the lymphocytes.

Lymphoid: Pertaining to lymphocytes or the lymphatic system.

Maintenance therapy: Extended treatment, usually given after the original treatment has brought the cancer under control. It is done to prevent the disease from relapsing or to keep the cancer in remission.

Malignant: A malignant tumour is a cancerous tumour. They can invade surrounding tissue and spread to other areas of the body. Benign tumours are not invasive and do not spread.

Mediastinum: The central area of the upper chest, located behind the breastbone.

Metastasis: The spread of cancer within the body from the original tumour site to other sites or organs.

Minimal residual disease (MRD): The term used when a very small number of cancer cells remain either during or after treatment.

Molecular genetic testing: Tests to find out what chromosome abnormalities and genetic changes are present in your CLL or SLL cells. See Genetic mutation.

Monoclonal: Derived from one cell. When diagnosing CLL, doctors are looking for monoclonal lymphocytosis, which means the cancer cells all derived from one original cell.

Monoclonal antibody therapy: A type of biologic therapy (or immunotherapy) used for cancer treatment. A synthetic antibody is created to target a specific protein on the surface of cells. This marks the cell so that the immune system will kill it.

MRI (magnetic resonance imaging): A technique used to obtain three-dimensional images of the body. While similar to a CT scan, an MRI uses magnets instead of X-rays.

Mucositis: Inflammation of the lining of the digestive tract, most commonly of the mouth, causing painful sores.

Myeloablative chemotherapy: High-dose chemotherapy that destroys the bone marrow. This is performed prior to a bone marrow or stem-cell transplant.

Myelosuppression: A reduction in bone marrow activity resulting in decreased red blood cells, white blood cells and platelets.

NHL: Non-Hodgkin lymphoma.

Nausea: A sensation characterized by an urge or need to vomit.

Neutropenia: A reduction in the number of neutrophils, the white blood cells that fight bacterial infection. This may put a patient at a higher risk of infection.

Neutrophils: The most common type of white blood cell in the body.

Night sweats: Extreme sweating during sleep at night.

Oncologist: A doctor who specializes in the treatment of cancer.

Oncology: The branch of medicine that focuses on the diagnosis and treatment of cancer.

Palliative: Treatment that is designed to relieve symptoms rather than cure disease.

Pancytopenia: Deficiency of all three types of blood cells (red cells, white cells, platelets).

Partial response: Also called partial remission. The term used when the cancer has decreased in size by half or more, but has not been completely eliminated. The cancer is still detectable and more treatment may be necessary.

Pathologist: A doctor who specializes in identifying diseases by examining and studying cells under a microscope.

Performance status: A term describing how well a patient is able to perform daily tasks and activities.

Peripheral blood: Blood circulating in the blood vessels and heart as opposed to the bone marrow.

Peripheral blood stem-cell transplant (PBSCT): See stem cell transplant.

Peripheral neuropathy: Altered nerve sensations in the hands and feet, including numbness, tingling and weakness as a result of nerve damage.

PET scan (positron emission tomography): A way to visualize cancer in the body. Radioactive glucose (a sugar molecule used as the energy source for cells) is injected into the patient and is taken up preferentially by cells with high metabolic activity, such as cancer cells. A scanner is then used to visualize the areas of the body where the radioactive glucose is concentrated.

PICC line: A peripherally-inserted central catheter (PICC) is a catheter inserted into a vein in the arm.

Plasma cell: The main function of plasma cells is antibody production. They play an important role in the defense against infection and disease.

Pleural effusion: A collection of fluid inside the chest cavity around the lungs.

Primary therapy: The first treatment given after a patient is diagnosed with cancer.

Prognosis: The prediction of the outcome of the cancer and the likelihood of recovery.

Prognostic factors: Along with the stage, there are other factors that help predict a person's outlook. These factors are sometimes taken into account when looking at possible treatment options. Factors that tend to be linked with shorter survival time are called adverse prognostic factors. Those that predict longer survival are favourable prognostic factors.

Radiation field: The area of the body that receives radiation therapy.

Radiation oncologist: A type of oncologist (cancer specialist) specializing in treating cancer with radiation therapy.

Radiation therapy or radiotherapy: A type of therapy where high-dose radiation beams (X-rays) are carefully focused on a tumour site. Exposure to the X-ray beams kills the cancer cells. For additional information, see page 65.

Rai staging system: Describes the extent to which a cancer has spread within the body. Classic Rai is staged between 0 and 4. The Modified Rai gives a risk level of low, intermediate or high. For additional information, see page 35.

Randomized controlled trial: A clinical trial that involves testing an experimental drug treatment in comparison with a control treatment.

Refractory disease: A cancer that does not respond to treatment or that relapses very soon after treatment is completed (for example within 6 to 12 months).

Regimen: The administration of a specific combination and dose of cancer medications following an arranged schedule.

Relapse: The return of cancer after a period of improvement.

Remission: A patient is said to be in remission if the cancer has diminished by half or more (partial remission) or is undetectable (complete remission). Remission does not necessarily mean that the cancer has been cured.

Richter's Syndrome (RS), also known as Richter's Transformation: A rare complication of CLL or SLL characterized by the sudden transformation of the CLL or SLL into a significantly more aggressive form of large cell lymphoma. For additional information, see page 87.

Salvage therapy: Treatment that is used when the cancer has not responded to initial treatments or after the cancer has relapsed.

Secondary cancer: A secondary cancer is a new cancer, which is different from the CLL or SLL you were initially treated for that develops after treatment for CLL or SLL. It may develop as a late effect of your initial treatments, such as chemotherapy and radiation.

Side effect: Secondary effect caused by cancer treatment. Side effects can be short-term (disappear quickly), long-term (last for a longer period of time) or a late-effect (develop months or years after treatment has ended). There are many effective treatments that can reduce side effects or prevent them from happening altogether.

Spleen: An organ that is an important part of the lymphatic system. The spleen is located in the top left-hand corner of the abdomen, below the ribcage. The spleen is involved in lymphocyte production and storage, and also works to store and filter the blood and remove aging blood cells from the circulation.

Splenectomy: Surgery to remove the spleen.

Splenomegaly: Abnormal enlargement of the spleen.

Stable disease: A term used when the cancer does not get better or worse following treatment.

Stage: Describes the extent to which a cancer has spread within the body. For additional information, see page 34.

Stem cell: A precursor cell produced in the bone marrow that gives rise to all different kinds of blood cells (red blood cells, white blood cells and platelets).

Stem cell transplant: A procedure that replaces stem cells destroyed by high-dose chemotherapy and radiation with healthy stem cells. For additional information, see page 66.

Subcutaneous (SC or SQ): Under the skin.

Supportive therapy or supportive care: Therapy given to prevent or treat CLL symptoms and/or treatment side effects.

Systemic: Affecting the entire body.

T cell (T lymphocyte): A subset of lymphocytes that recognize and destroy abnormal cells (e.g., virus-infected cells and cancer cells) and play an important role in fighting infection.

Thrombocytes: Also called platelets. They are small pieces of cell that help blood clot and stop bleeding.

Thrombocytopenia: A lower than normal level of platelets in the blood. Platelets are important in blood clotting and a shortage may result in increased bleeding or bruising.

Thymus gland: A gland that is part of the lymphatic system where T-cells complete their development. The thymus is located behind the sternum (breastbone) in the chest.

Tissue: A group of cells that work together to perform a specific function in the body.

Toxicity: Any unwanted side effect of medication. Common toxicities of cancer treatments include hair loss, nausea and vomiting.

Transformed CLL: CLL that has changed or transformed into a more aggressive form of lymphoma.

Treatment failure: A worsening of the cancer despite treatment. The term is often used interchangeably with the term disease progression.

Trisomy: Chromosome abnormality that includes the presence of an extra copy of a chromosome.

Tumour: An abnormal mass of dividing cells that serves no useful bodily function. Tumours can be either benign (non-cancerous) or malignant (cancerous).

Tumour burden: Refers to the number of cancer cells, the size of a tumor, or the amount of cancer in the body.

Tumour lysis syndrome (TLS): Tumour lysis syndrome (TLS) is a potential complication during cancer treatment, caused by an anticancer drug triggering the quick death of a large number of cancer cells, making them break apart and enter the bloodstream. The kidneys can't properly filter the cellular contents of the dying cells from the blood. TLS is a group of problems involving the blood - high blood potassium, high blood phosphorus, low blood calcium and high blood uric acid. This is a potentially fatal complication, and patients at increased risk for TLS should be closely monitored before, during, and after their course of treatment.

Ultrasound: Ultrasound imaging uses sound waves to produce pictures of the inside of the body.

Venous catheter: A device, usually a flexible tube, which is used to give medications into the body (through a vein) or take fluids (e.g., urine) out of the body.

Watch and wait: An approach to cancer where patients have no serious symptoms so no immediate treatment is given after diagnosis. Patients are closely monitored through regular visits with their doctor to ensure the cancer is not progressing. This strategy is often appropriate for patients with CLL and SLL.

Xerostomia: A reduction in the production of saliva resulting in a dry mouth. It can be a side effect of cancer treatment.

X-ray: Radiation beams that are used in two ways: in low doses to provide images of the inside of the body for diagnostic purposes and in high doses to treat cancer (radiation therapy).

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