



Chronic Lymphocytic Leukemia Treatment Discussion Guide

You and your medical team have decided it's time to treat your CLL

WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with chronic lymphocytic leukemia (CLL), a type of blood cancer that affects white blood cells called lymphocytes. Beyond active surveillance (the 'watch and wait approach') there are several CLL treatments to consider. Each treatment has different features and side effects.

It is important to be comfortable with the CLL treatment you choose. This choice starts with having an open conversation with your medical team for well-informed, shared decision making.

This discussion guide will take you through three steps so you can:

- 
- 1** Document your personal information and preferences
 - 2** Know your CLL treatment options
 - 3** Discuss treatment options with your medical team

1

Document your personal information and preferences

You can print out this page, fill in these questions, and take your answers to the next appointment where you and your medical team discuss your CLL treatment options.

About you

Does your CLL have a 17p deletion / TP53?

☐ Yes ☐ No ☐ I don't know

Are you older than 70?

☐ Yes ☐ No

Do you have private medical insurance?

☐ Yes ☐ No

Do you think you are in good health?

☐ Yes ☐ No

Are you on heart medications?

☐ Yes ☐ No

Do you have a history of bleeding problems?

☐ Yes ☐ No

Are you on blood thinners?

☐ Yes ☐ No

How easy is it for you to swallow pills?

Very easy ☐ ☐ ☐ ☐ Very difficult

How easy is it for you to remember to take your medication every day at the correct time?

Very easy ☐ ☐ ☐ ☐ Very difficult

How do you feel about bloodwork (blood sample taken from you by needle or finger prick)?

☐ I don't mind it is easy for me

☐ It is difficult for me

Do you live close to, or far from, the hospital where you would get cancer treatment?

_____ km

How easy is it for you to travel to a hospital for treatment

Very easy ☐ ☐ ☐ ☐ Very difficult

Do you have mobility issues (disability, lack of transportation)?

☐ Yes ☐ No

Are you able to spend half a day once a month in a hospital for treatment?

☐ Yes ☐ No

About treatment

Do you know what remission is?

☐ Yes ☐ No ☐ I don't know

Are you aware of the side effects of treatments?

☐ Yes ☐ No

Would you prefer...

☐ to take a long-term oral medication every day (potentially for years)?

OR

☐ a short-term combination oral and intravenous treatment that lasts approximately a year? This requires initial monthly hospital visits.

OR

☐ a short-term, all oral combination treatment that lasts approximately a year? This requires initial monthly hospital visits



2

Know your CLL treatment options

Not everyone receives the same treatment for CLL. Some options may be given in combination with others, and your treatment may change as time goes on.

CLL Treatment Beyond Active Surveillance

	Chemotherapy	Targeted therapy	Antibody therapy	Stem cell transplant
Treatment options	Drugs that kill rapidly dividing cells. Some of the major types of chemotherapy drugs include purine analogs, and alkylating agents.	Drugs targeting specific proteins in cancer cells that are not found in normal cells. Drug types that fall under this category include Bruton's tyrosine kinase (BTK) inhibitors, PI3K inhibitors and BCL-2 inhibitors, and others.	Type of immunotherapy that marks cancer cells so they can be found and destroyed by your immune system. Antibody therapy can also target a specific protein such as CD20.	Procedure where new, healthy stem cells are removed from yourself - or, more commonly, from a donor - to restore your bone marrow to health. It is also referred to as a bone marrow transplant.
Mode of administration	Injected into a vein.	Available in pill form, which makes it easier to take at home.	Injected through a needle directly into a vein, or injected into the tissue layer directly under the skin.	The new stem cells are injected into a vein through an intravenous (IV) catheter or tube.
Treatment duration	Treatment lasts 2 to 3 days every 4 weeks. This is called a cycle and is usually ongoing for 6 months or 6 cycles.	Some drugs may be taken long term, while other drugs are taken for approximately one year.	Treatment may last for a few months or longer, as these drugs are most often given in combination with chemotherapy or targeted therapy.	Several steps are involved in receiving a stem cell transplant, which may take a few weeks or months.
Possible side effects	Normal, non-cancerous cells can also be affected by chemotherapy, which can lead to side effects such as: • Hair loss • Mouth sores • Loss of appetite • Nausea and vomiting • Low blood counts The complete list of side effects may depend on the specific drug, dose, and length of treatment.	Side effects may include: • Bleeding • Heart rhythm changes • Infections • Low blood counts • Diarrhea • Nausea • Constipation • Fatigue • Body aches • Rash The complete list of side effects may depend on the specific drug, dose, and length of treatment.	Side effects may include: • Reactions to the IV (itching chills, fever, nausea, rashes, fatigue, and headaches) • Low blood counts • Serious infections The complete list of side effects may depend on the specific drug, dose, and length of treatment.	A stem cell transplant can cause severe or even life-threatening complications and side effects - it is often not a good option in people who are older or have other health problems.

3

Discuss treatment options with your medical team

As well as these CLL treatment options, clinical trials test potential new ways of fighting cancer in people. Ask your medical team about the option of a clinical trial for you.

It's your blood cancer experience – participate in your treatment decisions. Have an honest conversation with your medical team, including questions or concerns about any of the CLL treatment options.

Here are some additional questions to consider.

- What tests will I need before we can decide on treatment?
- What should I do to be ready for treatment?
- Which treatment do you recommend for me? Why?
- What is the treatment frequency?
- How often will you test my blood or bone marrow throughout treatment?
- What are the possible risks or side effects? How serious are they and what should I report right away?
- How can I manage the side effects?
- Can treatments be taken at home?
- How will treatment affect my daily activities and habits, such as eating, exercising, taking other medications, etc.?
- What if I miss a treatment?
- What costs will I encounter?
- In cases of emergency, how can I reach your office on nights, holidays, or weekends?
- Are there subsidies for parking and travel to treatment?

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

LLSC gratefully acknowledges Dr. Mary-Margaret Keating, MEd MD FRCPC, Division of Hematologic Oncology, QEII Health Science Center, Halifax, Nova Scotia, for her important contribution to the content of this publication.

This publication was made possible thanks to the support of:

abbvie

AstraZeneca

BeOne

Distribution partner:

Johnson & Johnson



LEUKEMIA &
LYMPHOMA
SOCIETY OF
CANADA*

Never hesitate to contact us, we're here to help!

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