

I Have a CLL/SLL Diagnosis and Have Never Been on Treatment

Finding out that you have chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL), which are types of blood cancers, may feel scary and confusing. This guide can help you talk with your healthcare team about what matters most to you and which treatment options might best fit your life. Use this guide to support shared decision-making discussions, and always make treatment choices together with your healthcare team.

CLL/SLL may grow slowly, which means that it is a chronic disease, so treating it immediately may not be required. Your doctor may recommend what is called “active surveillance” or “watch and wait” after your diagnosis. This means that treatment does not start right away. Instead, the cancer is monitored with visits and tests. Feeling anxious is normal, but active surveillance is not the same as doing nothing; there is a clear plan to act if tests show that the cancer is changing.

Not all CLL/SLL treatments are right for everyone, so it is important to learn what to consider before choosing a treatment.

Before your visit

Reflect on what matters most to you.

Check the preferences that matter most to you to inform your discussion with your healthcare team:

- ☐ Have a treatment that is as effective as possible
- ☐ Have minimal side effects from treatment
- ☐ Be able to maintain normal daily activities
- ☐ Have a simple treatment routine that is easy to follow
- ☐ Be able to pay for treatment
- ☐ Be able to get to my appointments without too much stress
- ☐ Many people with CLL/SLL may have other health conditions and symptoms, sometimes called comorbidities.
- ☐ Common comorbidities for people living with CLL/SLL include heart conditions, high blood pressure, diabetes, and kidney (renal) issues.
- ☐ Before your visit, write down any other health conditions, medications, and symptoms you want to discuss with your doctor because your health history may affect which treatment may be right for you.

1

Your doctor looks at many things when deciding to start treatment or choosing the right treatment for you. This includes: your age, your overall health, how your CLL/SLL is progressing, how well a treatment may work, their own clinical experience treating patients, what potential side effects may be, and what potential impact a treatment may have on your daily life or lifestyle.

Another important consideration is whether your CLL/SLL has certain biological or genetic features, such as IGHV mutation status, deletion 17p, or TP53 abnormalities, which may influence disease behavior, prognosis and treatment options.

For people with CLL/SLL who also have other health conditions, it is important to discuss with your doctor how these conditions may affect CLL/SLL management.

Always share your full health history with your or healthcare team so that you can make a decision together about which treatment options is the right choice for you.

Ask Your Doctor: How does my specific situation - including my age, overall health, genetic features, mutation status, other health conditions, and how my CLL/SLL is progressing - influence whether you keep watching with active surveillance or start treatment?

- If treatment is needed, which options are best for me?
- Are there test results, biomarkers, or health conditions that could make certain treatment approaches more or less appropriate for me?

2

CLL/SLL may be treated with continuous daily oral medication, or stopped after a scheduled period of time treatments. Fixed-duration treatments can include treatment that is infused through an IV at your doctor's office.

Continuous daily oral medication can be taken at home with a steady routine, while fixed-duration treatment may require several visits during the beginning of treatment, regular trips to the clinic for infusions, and potential hospitalization for observation.

There are two treatment approaches your doctor may discuss: a continuous regimen and a fixed-duration regimen.

Continuous treatment generally means taking one type of oral medication every day at home until it no longer works to treat the disease.

Fixed-duration treatment generally means taking multiple medications for a certain period of time; some patients may then have a treatment-free period, depending on their response.

When comparing treatment options, consider how much time you may spend at appointments, infusions, and monitoring; how easy it may be to stick to the schedule; and how the plan may fit curtail - lifestyle, mental health, age, and overall fitness.

Ask Your Doctor: When discussing treatment options, describe what the first few months of treatment management looks like, including, visits, lab tests, potential hospitalizations, infusions at the clinic, and treatments at home?

- Is each option a continuous regimen or a fixed-duration regimen?
- How will my health history, test results, and lifestyle affect which approach may fit best?
- What are the main differences in side effects, monitoring, and time commitment between these options?

3

Because CLL/SLL is a chronic disease, it is important to understand how you might respond to treatment over time. Certain treatments may have been studied in patients for a long period of time, while some newer treatment options have been studied for shorter time.

Ask your doctor how long each treatment has been studied and how the results affect treatment decisions.

Ask Your Doctor: Which treatments have been studied over many years?

- What are other factors to consider when deciding which treatment option is best for the diagnosis and best fits my situation and treatment goals?
- What treatment data should be discussed before deciding between a continuous regimen and a fixed-duration regimen?
- Which treatments have efficacy and safety results at 5, 6, or 7+ years?

4

Choosing a CLL/SLL treatment often involves comparing how different treatments affect daily lifestyle, life, and it is important to know that all CLL/SLL treatments have side effects. Some side effects may be temporary and improve with time, while others may persist or worsen.

Chemotherapy-based treatment may have long-term complications. While some treatments called “targeted therapies” are designed to target specific proteins and pathways involved in cancer growth. They too may still cause unique issues like heart rhythm changes or issues with blood clotting. The side effects of each specific medication should be discussed with your doctor when selecting a treatment.

Even “mild” side effects like feeling tired, headaches, or pain, may differ between targeted therapy options. Discuss these possibilities with your doctor or healthcare team.

When evaluating treatment options, talk to your doctor about what side effects to expect and whether any treatments carry a risk of tumor lysis syndrome (TLS), a serious side effect caused by the rapid breakdown of cancer cells.

Ask Your Doctor: What do studies say about side effects and how patients feel daily options you are considering for me?

- How might the treatment choice affect energy levels, sleep, and daily activities?
- What side effects differences are seen with a continuous regimen versus a fixed-duration regimen?

4

CLL/SLL and some treatments may weaken your body’s defense system against germs (your immune system). This may increase the risk of infections and may reduce how well some vaccines work.

Tell your doctor about any heart conditions, high blood pressure, diabetes, kidney problems, or other health conditions, as these may affect treatment choices and monitoring.

When evaluating treatment options, talk to your doctor about any medical conditions and high-risk factors, as well as monitoring and potential hospitalization.

Ask Your Doctor: How does CLL/SLL, and each treatment choice, affect the body’s defense system?

- How well will vaccines work, and what can be done to lower my risk of infections?
- Are there any precautions to consider?
- Could certain health conditions affect treatment options? other health conditions affect which treatment approach may be better for me?