

I Have a CLL Diagnosis and Was Previously on Treatment but Am Not Currently on Treatment

After finishing or stopping chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL) treatment, it may be hard to know what comes next or how to plan ahead. This guide can help you in shared decision-making discussions with your care team about follow-up, future options, and what matters most to you now.

As your journey with CLL/SLL continues, the choices for subsequent treatments may be influenced by your previous treatments and your current overall health. With the help of your care team, it is important to understand the nuances of each option in terms of how the treatment has been studied, what side effects it may cause, how and how often the treatment is taken, and how long to take the treatment.

If your CLL/SLL needs treatment again, clinical data can help you and your care team discuss options by looking at how long people benefited from treatment, what side effects were reported, and how long patients were followed in studies.

Because your next treatment choices may depend on your previous treatment and current health, it is important to discuss any other health conditions you may have with your doctor.

Before your visit

Reflect on what matters most to you.

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

- ☐ Stay on a treatment that is as effective as possible
- ☐ Have fewer side effects from treatment
- ☐ Have enough energy and comfort to do daily activities
- ☐ Have a clear, simple plan so that I know what to expect at follow-up visits
- ☐ Be able to access future treatments without too much financial strain
- ☐ Choose treatment that is logistically easier to manage (such as managing refills and travel)
- ☐ Bring a list of the treatment or treatments you have already had, why they were stopped, and any side effects that mattered most to you
- ☐ Also bring a list of other health conditions, medications, and any heart, blood pressure, diabetes, or kidney concerns you want to discuss
- ☐ If your doctor discusses future treatment options, ask what the data show about how long people did well on treatment and what side effects were reported.

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The type of CLL/SLL treatment you had before, how well it worked, and why it was stopped are key factors in deciding which treatments to use next.

It is important to discuss with your doctor any health conditions you may have, since your health history may affect which treatment may be right for you. Always share your full health history with your doctor so you can make a decision together.

Ask the Doctor:

- Can you explain which treatment or treatments I had previously, how well they worked, and why we stopped them?
- How do my previous treatments help decide which options are best for me if or when my CLL/SLL needs treatment again?
- How could my current health conditions or medications affect which next treatment options might be right for me?

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Regular check-ups and blood tests help find CLL/SLL changes early, and certain lab changes, together with symptoms and other signs of disease activity, help doctors determine whether treatment is needed again.

If you notice new or worsening symptoms, ask your doctor whether those changes could be related to CLL/SLL progression, treatment effects, another health issue, or a rare but serious change called Richter's transformation.

Richter's transformation is a rare but serious change that can happen in people who have CLL/SLL.

While CLL/SLL are slow-growing blood cancers, in Richter's transformation, the cancer changes into a faster-growing type of lymphoma.

It is important to know that Richter's transformation is not your fault. There is nothing you did to cause it

Ask the Doctor:

- How often do you want to see me for testing?
- Which changes in my test results or symptoms would make you think my CLL/SLL is active again and needs treatment?
- Are there new or worsening symptoms that should make me contact you sooner because of concern for a faster-growing lymphoma such as Richter's transformation?

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When CLL/SLL comes back, common treatment options may again include continuous daily oral medication or treatments that are stopped after a set time, called “fixed-duration” treatments. For some patients, other may include chemotherapy, other targeted therapies, CAR-T therapy, or a stem cell transplant. Each approach has trade-offs in how long you stay on treatment, how often you come to the clinic, and how it may affect your future choices.

Continuous treatment plans may be taken at home with a steady routine, while fixed-duration treatment may require several visits during the beginning of treatment, regular visits to the clinic for infusions and, in some cases, hospitalization for observation depending on risk factors.

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

Learning how these approaches differ, and how your personal health and biomarkers influence treatment, can help you and your doctor choose a plan with confidence.

It is important to discuss with your care team all the factors that impact which option may be best for your situation.

To ask more specific questions about future treatment questions, consider looking at clinical trial data, such as how long patients benefited from treatment, how often side effects occurred, and how long patients were followed in the study.

Progression-Free Survival (PFS) is a measure of how long patients lived without their cancer getting worse or until death.

Overall Survival (OS) is a measure of how long patients lived after starting treatment.

Follow-up time is how long researchers continued checking on patients after treatment began.

Ask the Doctor:

- Given my past treatment and current health, what are the main pros and cons of continuous treatment or fixed-duration treatment for me?
- How would each approach affect effectiveness, side effects, clinic visits, monitoring, and daily living?
- If we discuss clinical trial data, can you explain what PFS, OS, and follow-up time mean for my specific situation?
- Are there clinical trials or next-line options I should understand now, even if I do not need treatment immediately?

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CLL/SLL and some treatments can suppress the immune system, which may increase the risk of infections and may reduce how well vaccines work, even several months after treatment has stopped.

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

Ask the Doctor:

- How is my immune system doing now after my last treatment?
- What vaccines, preventive treatments, or lifestyle changes do you recommend to help protect me from infections?
- How could my other health conditions affect monitoring or the choice of a future treatment?
- Could any of my medications or health conditions affect whether continuous treatment or fixed-duration treatment is safer for me?

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Trusted healthcare resources can help you prepare for future treatment decisions, especially when they explain clinical trial data, side effects, relapse monitoring, Richter's transformation, and other health conditions in language you can discuss with your healthcare team.

Examples of trusted resources may include your healthcare team, clinic or health-system education materials, patient navigators, and reputable cancer organizations.

Ask the Doctor:

- If my CLL/SLL needs treatment again, can we outline what the next treatment-planning conversation would look like?
- Are there trusted healthcare resources you recommend so I can review information on my own?
- Which resources are most relevant for me right now: clinical trial data, side-effect tables, relapse monitoring,
- Richter's transformation, or managing other health conditions?