

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

After finishing or stopping CLL 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 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's 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.

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)

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

Ask Your Doctor: Can you explain which treatment(s) I had previously, how well it worked, why we stopped it, and how these previous treatment(s) help decide which options are best for me if or when my CLL needs treatment again?

- 2** Regular check-ups and blood tests help find CLL changes early, and certain lab changes or symptoms are used to decide when or if treatment is needed again.

Ask Your Doctor: How often do you want to see me for testing, and which changes in my test results or symptoms would make you think my CLL is active again and needs treatment?

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When CLL comes back, more common treatment options may again include continuous daily oral medication or treatments that are stopped after a set time, called “fixed duration” treatments. Other treatment options may include chemotherapy, other targeted therapies, CAR-T therapy (personalized immunotherapy), 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 may require several visits during the beginning of treatment, regular visits to the clinic for infusions, and potential hospitalization for observation.

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

Ask Your Doctor: Given my past treatment and health, what are the main pros and cons of a continuous daily treatment versus a fixed duration treatment approach for me, in terms of effectiveness, side effects, and daily living? Which treatments have strong survival outcomes at 5, 6, or 7+ years?

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CLL 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.

Ask Your Doctor: How is my immune system doing now after my last treatment, and what vaccines, preventive treatments, or lifestyle changes do you recommend to help protect me from infections?

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Additional education materials can help patients and families feel more prepared for future treatment decisions.

Ask Your Doctor: If my CLL needs treatment again, can we outline a treatment plan? Are there trusted resources you recommend so I can research on my own?