

I Have a CLL Diagnosis and Have Never Been on Treatment

Finding out that you have Chronic Lymphocytic Leukemia (CLL), a kind of blood cancer, may feel scary and confusing. This guide can help you talk with your care team about what matters most to you, which treatment choices might best fit your life, and help you to make decisions with your healthcare team. Use this guide to support shared decision-making discussions, and always make treatment choices together with your healthcare team.

CLL is a cancer that 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.

When it is time to start therapy, it is important to know that CLL has more than one treatment choice. Each treatment works in different ways, and each has its own pros and cons: how it has been studied, what side effects it may cause, how and how often the treatment is taken, and how long you stay on it.

Some treatments may not be right for every type of patient, so it is important to understand which treatments may be right for your circumstances and may be available to you. When starting treatment, you should also talk to your doctor about how the treatment you choose today may affect your treatment options later.

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:

- 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

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 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 sub-type carries a mutation (change in DNA), such as IgHV, deletion 17p, or TP53, that can affect the disease progression and treatment options.

Ask Your Doctor: How does my specific situation – including my age, overall health, mutation status, and how my CLL is progressing – influence whether you keep watching with active surveillance or start treatment? If we are starting treatment, which options are best for me? If I have a mutation, are there certain treatments that perform better in that mutation type?

- 2** CLL may be treated with continuous daily oral medication, or with treatments that are stopped after a set time, called “fixed duration” treatments. Fixed duration treatments can include a 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 may require several visits during the beginning of treatment, regular trips to the clinic for infusions, and potential hospitalization for observation.

Ask Your Doctor: For my main treatment options, can you walk me through what my first few months would look like, including visits, lab tests, potential hospitalizations, infusions at the clinic, and treatments at home? How will you decide what fits my life and treatment goals the best? If I have a certain mutation, is there a difference in how “fixed duration” and continuous treatment perform in my mutation type?

- 3** Because CLL is a chronic disease, it's 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 options may not be as well understood. This means that certain treatments have better long-term survival outcomes than others.

Ask Your Doctor: Which treatments have been studied over many years? What are other factors you will consider when deciding which option best fits my situation and treatment goals? Which treatments have strong progression-free and overall survival outcomes at 5, 6, or 7+ years?

- 4** Choosing a CLL treatment often involves comparing how different treatments affect your daily life, and it is important to know that all CLL treatments have side effects. Some side effects may go away or improve after a short while, while some may continue or even get worse.

Chemotherapy-based treatment may have long-term complications. While some treatments called “targeted therapies” focus more on the cancer, 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 considered by your doctor when selecting a treatment.

Even “mild” side effects like feeling tired, headaches, or pain, may differ between targeted therapy choices and could affect your experience. You should discuss these possibilities with your doctor about these upfront.

Ask Your Doctor: What do studies say about side effects and how patients feel day-to-day on the treatment options you are considering for me? How might the treatment you choose affect my energy, sleep, and my daily activities? What resources are available to help me navigate this? How will the side effects on this treatment change over time?

- 5** CLL and some treatments may weaken your body’s defense system against germs (your immune system). This may make it easier to get infections and can sometimes make vaccines work less well.

Ask Your Doctor: How does CLL, and each treatment choice, affect my body’s defense system? How well will vaccines work for me and what can we do to lower my risk of infections? What are some precautions I may need to take?