# I Am a Caregiver for Someone Living With CLL

Helping someone you care about with Chronic Lymphocytic Leukemia (CLL) may be stressful and confusing, especially at doctor visits. This guide can help you share what you see at home and ask questions that support both you and your loved one. Use this guide to support shared decision making discussions, and always make treatment choices together with the healthcare team.

## My loved one is newly diagnosed

CLL is a cancer that may grow slowly, which means that it is a chronic disease, so treating it immediately may not be required. Sometimes, your loved one's doctor will recommend what is called "active surveillance" or "watch and wait" after their diagnosis. This means that treatment doesn't start right away. Instead, the cancer is checked closely with regular 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 the cancer is changing.

## My loved one is about to start treatment

When it is time to start treatment, there are several different options, and people with CLL may have more than one kind of treatment over time. Each treatment works in different ways, and each has different 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 someone will stay on it. As your loved one's journey with CLL continues, the choices for subsequent treatments may be influenced by their previous treatments and their current overall health. As a caregiver, knowing these factors may help you ask questions and support your loved one in choosing what makes sense now and later.

## My loved one is undergoing treatment currently, or was previously on treatment

Helping track symptoms and side effects to help inform the healthcare team can be a meaningful way to support your loved one.

### Before your visit

Reflect on what matters most to you.

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

- ☐ Help my loved one live as long as possible
- ☐ Help my loved one have fewer or less uncomfortable side effects from treatment
- ☐ Keep caregiving and daily life at a level I can handle
- ☐ Have a simple care plan at home that I can realistically follow
- ☐ Choose care that we can manage financially (such as cost and insurance)
- ☐ Choose care that we can manage logistically (such as appointments, refills, and travel)

Caregivers often give rides, help schedule visits, help with treatment at home, and watch for and assist with side effects. Your needs and limits should be part of planning treatment. Take a moment before the visit to think about what you can and cannot realistically help your loved one with.

1. Caregivers give important support, but you may have limits with work, travel, and other duties. These limits may affect which treatment plans are convenient for you.

   **Ask the Doctor:** Are there treatment options that may be easier or harder for us to manage? Here is what I can realistically help with (rides, time off work, staying during infusions, and help at home).

2. Clear, written instructions about the treatment steps, symptoms and warning signs may help you know what to do and when to call the doctor if something seems wrong.

   **Ask the Doctor:** Can you explain in simple terms what the next 6-12 months look like and which symptoms or side effects you want us to call you about right away? Can we write them down so that we have it at home?

3. 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 may include a treatment that is infused through an IV at a doctor’s office.

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

   **Ask the Doctor:** For the main treatment options, what does a typical month of visits, infusions, and blood tests look like? Are there choices that might be easier on our schedule while still being safe and effective?

4. CLL itself, as well as the treatments for CLL, may make it easier to get infections. Simple steps to prevent infection at home and in public are very important.

   **Ask the Doctor:** How does CLL and my loved one’s treatment affect their infection risk, and is there anything we can do at home to reduce infection risk?

5. What your loved one tells you about their symptoms, and what you see in their daily life, may show when a treatment is too hard on them, even if lab results look good.

   **Ask the Doctor:** From your point of view, when would fatigue, mood changes, sleep problems, or limits on daily activities be serious enough that you would consider adjusting the dose or changing treatment? How can I best share what I see at home?

6. Emotional stress and burnout may be common for caregivers, and support services can help both patients and families.

   **Ask the Doctor:** Are there social workers, nurses, patient navigators, or support groups you recommend for us, including caregiver support? If I am worried about burning out or making a mistake, how can I reach out to the team?