

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.

As a care partner, you may be the person who notices changes in daily routines, symptoms, side effects, medication use, appointments, or stress levels between visits.

Make sure to bring up what you notice at home because those details may help the healthcare team understand how CLL/SLL or treatment is affecting daily life

My loved one is newly diagnosed

CLL/SLL 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/observation" or "watch and wait" after diagnosis. This means that treatment does not start right away. Instead, the cancer is checked closely with regular visits and tests. Feeling anxious is normal, but active surveillance/observation is not the same as doing nothing; there is a clear plan to act if tests show the cancer is changing.

Care partners like you can help by keeping track of questions, symptoms, medicines, and other concerns to discuss at the next visit.

My loved one is about to start treatment

When it is time to start treatment, there are several different options, and people with CLL/SLL 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, the side effects it may cause, how and how often it is taken, and how long someone will stay on it. As your loved one's journey with CLL/SLL continues, the choices for subsequent treatments may be influenced by previous treatments and current overall health. As a care partner, knowing these factors may help you ask questions and support your loved one in choosing what makes sense now and later.

It is important to discuss with the doctor any health conditions (such as high blood pressure, diabetes, and/or kidney problems) your loved one may have, since health history may affect which treatment is right for them.

Treatment schedules can also vary between treatments, so it may be helpful to understand how often treatment is taken, how long it may last, and what support your loved one may need at home.

When dealing with a new diagnosis of CLL/SLL, it is important to ask your doctor to test your loved one for genetic changes and biomarkers that can affect how CLL/SLL may behave and how treatments may work. that can affect how CLL/SLL will progress and how CLL/SLL treatments may work

Ask the Doctor:

- Have you tested for IGHV, deletion 17p, or TP53?
- How do the test results affect how you are thinking about treatment options?
- Are there other health conditions or medicines we should discuss before choosing treatment?
- Would each treatment option be continuous treatment or fixed-duration treatment?

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

When reviewing treatment information from clinical studies, it may help to understand how long patients benefited from treatment, how long patients lived after starting treatment, and how long researchers continued studying the treatment.

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:

- What should we understand about how long this treatment may continue to work?
- How should we interpret these study results for my loved one's situation?
- What side effects were most common or most serious in the studies you are using to guide this treatment decision?

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)
- ☐ Before the visit, write down what you can realistically help with, including rides, time off work, staying during infusions, refills, medication routines, and help at home.
- ☐ Also write down any other health conditions, medicines, supplements, symptoms, or side effects you have noticed.
- ☐ If your loved one is taking treatment at home, ask what to do if a dose is missed, delayed, or taken differently than planned.
- ☐ Ask whether treatment is continuous or fixed-duration and what that may mean for home support and scheduling.

1

Care partners 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.

Care partners 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, refills, medication routines, and help at home.
- Could my loved one's other health conditions or medications make one plan easier or harder to manage safely at home?
- What support may be needed at home for continuous treatment or fixed-duration treatment?

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.

When reviewing side effects, ask which symptoms are expected, which need closer monitoring, and which should prompt a call right away

Ask the Doctor:

- Can you explain in simple terms what the next 6–12 months look like?
- Which symptoms or side effects do you want us to call about right away?
- Can we write the warning signs down so that we have them at home?
- Which side effects should we track at home, and which ones require calling the care team right away?

3

CLL/SLL 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 treatment that is infused through an IV at a doctor's office.

Continuous treatment can often be taken at home with a steady routine, while fixed-duration treatment may require more visits at the beginning of treatment, regular trips to the clinic for infusions, and possible monitoring or hospitalization depending on the treatment and the patient's risk factors.

These approaches may differ in clinic visits, monitoring requirements, treatment schedules, and what support is needed at home.

Ask the Doctor:

- Can you explain in simple terms what the next 6–12 months look like?
- Which symptoms or side effects do you want us to call about right away?
- Can we write the warning signs down so that we have them at home?
- Which side effects should we track at home, and which ones require calling the care team right away?

4

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

Tell the healthcare team about any heart conditions, high blood pressure, diabetes, kidney problems, or other health conditions, as these may affect treatment decisions and monitoring.

Ask the Doctor:

- How does CLL/SLL and my loved one's treatment affect their infection risk?
- Is there anything we can do at home to reduce infection risk?
- Should we be watching for anything differently because of my loved one's other health conditions?

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?
- Can you help us understand which side effects are common, which are serious, and which might affect daily life the most?

6

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

If you notice new or worsening symptoms, ask the healthcare team whether those changes could be related to CLL/SLL progression or another condition that should be evaluated, since rare conditions may emerge later in the disease course.

Ask the Doctor:

- Are there social workers, nurses, patient navigators, or support groups you recommend for us, including care partner support?
- If I am worried about burning out or making a mistake, how can I reach out to the team?
- Are there any new or worsening symptoms that should make us contact you sooner because of concern for a faster-growing lymphoma such as Richter's transformation?