

# I Have a CLL Diagnosis And Am Currently on Treatment

Treating your CLL may bring up many questions and worries. This guide can help you check how things are going and support you in having clear, honest conversations with your care team. Use the guide to support shared decision-making discussions, and always make treatment choices together with your healthcare team.

## 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 treatment routine that I can reliably stick with over time, including while traveling
- Choose treatment that I can manage financially

1

Over time, how well your CLL is controlled, your side effects, and your daily functioning may change, so your treatment plan may need to be reviewed. 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 the treatment is taken and how often, and how long you stay on it. Because CLL is a chronic disease, it is also important to know how today's treatment may affect what you potentially may use later and how well your treatment performs over the long term.

**Ask Your Doctor:** Based on how my CLL is responding to treatment and how I've been feeling, do you still think this is the best treatment for me, or are there other options we should talk about now or in the near future? Does my treatment have strong survival outcomes at 5, 6, or 7+ years? If not, is there another treatment that does?

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 may include a treatment that is infused through an IV at your doctor's office.

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 trips to the clinic for infusions, and potential hospitalization for observation.

**Ask Your Doctor:** Given how my CLL has been responding to my treatment and how well I have been tolerating the side effects, do you feel my current schedule of visits, tests, and how I take my medicine is still the best treatment option for me? If I am on "fixed duration" treatment, do you expect that I will start a continuous daily oral medication next? If so, which ones have strong long-term survival outcomes?

**3**

Many CLL treatments are taken for long periods of time, and side effects that seem manageable early on may add up over months or years. Studies and real-world data have shown that there may be a difference in these “nuisance” side effects, such as pain, headache, or feeling tired. Treatment decisions should be based not only on disease control, but also on whether the ongoing burden of side effects remains acceptable to you.

**Ask Your Doctor:** Are the side effects I’m experiencing expected for this treatment? Has the overall burden become high enough that we may consider adjusting my treatment plan? Do you expect that my side effects will improve or get worse over time? Are there other treatments that have strong side effect profiles over the long term?

**4**

All CLL treatment plans require regular check-ups to monitor how well the treatment is working and to watch for side effects (e.g. infections or those that effect vital organs such as heart and liver). How often you’ll need visits and tests depends on which treatment you receive.

Both continuous therapy & fixed duration treatment types have side effects for which you will be monitored. While they share certain side effects, some are more common in continuous therapy than in fixed duration, and vice-versa.

For example, continuous therapy (daily oral medication) options may be associated with fatigue, headaches, and some heart-related problems, although newer treatments have been shown to cause fewer heart-related problems than older ones. Fixed duration therapy (which may include IV administration) may be associated with infections and “tumor lysis syndrome,” which may require special monitoring depending on the patient’s CLL risk.

**Ask Your Doctor:** Given my health history and how long I may stay on this type of treatment, how will you monitor side effects, and are there things we can do to help mitigate these risks? Are there certain treatments that have side effect profiles that are easier to manage?