

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.

Because you are currently on treatment, this guide can help you bring up day-to-day concerns to your doctor, such as how you take your medication, side effects, other health conditions, and whether your current plan still fits your goals

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
- ☐ Write down all medicines, supplements, and other health conditions you want to discuss, especially heart conditions, high blood pressure, diabetes, or kidney issues.
- ☐ Take note of missed or delayed doses, changes in how you take your treatment, new side effects, or symptoms that are affecting your daily life.
- ☐ If you are unsure whether your treatment is continuous or fixed-duration, write that down as a question to ask your doctor.

1

Over time, how well your CLL/SLL is controlled, your side effects, and your daily functioning may change, so your treatment plan may need to be reviewed.

Because CLL/SLL is a chronic disease, it is also important to know how today's treatment may affect curtail - your future treatment options and how well your treatment performs over the long term.

You should discuss with your doctor any health conditions you may have, since your health history may affect which treatment may be right for you.

Ask the Doctor:

- Based on how my CLL/SLL is responding to treatment and how I have been feeling, do you still think this is the best treatment for me?
- Are there reasons to continue, adjust, or switch my treatment based on my response, side effects, goals, health history, or other medicines?
- If we are considering a change, would the next option be continuous treatment, fixed-duration treatment, or another approach?

2

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 your doctor’s office.

Continuous treatment plans may be taken at home with a steady routine, while fixed-duration treatment may require several visits during the beginning of treatment, regular trips to the clinic for infusions and, in some cases, hospitalization for observation.

Continuous treatment generally means taking an oral medication on an ongoing basis for as long as it continues to provide benefit and remains appropriate for you.

Fixed-duration treatment generally means taking treatment for a defined period of time, after which treatment is stopped.

When choosing or staying on a treatment, it is important to consider how a medicine works in your body because that can affect how and when it is dosed.

Ask the Doctor:

- Am I currently on a continuous regimen or a fixed-duration regimen?
- How and when should I take my treatment each day or each cycle?
- What should I do if I miss or delay a dose?
- Could food, other medicines, or supplements affect how my treatment works?
- If my treatment is fixed-duration and carries a risk of tumor lysis syndrome (TLS), what monitoring, blood work, or precautions do I need to follow?
- What ongoing monitoring do I need to do for continuous treatment?

3

Many CLL/SLL 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 that treatments may differ in the day-to-day side effects people experience, 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.

Healthcare providers may assign side effects a grade from 1 to 5 based on their severity.

Ask the Doctor:

- Are the side effects I am experiencing expected for this treatment?
- Which of my side effects are mild, which need closer monitoring, and which should prompt me to contact the care team right away?
- Has the overall burden of side effects become high enough that we should consider adjusting my treatment plan?
- Do you expect my side effects to improve, stay the same, or get worse over time?

4

All CLL/SLL treatment plans require regular check-ups to monitor how well the treatment is working and to watch for side effects, including infections or side effects that affect vital organs such as the heart and liver.

How often you need visits and tests depends on which treatment you receive.

Both continuous therapy and fixed-duration treatment types have side effects that require monitoring.

While they share certain side effects, some may be more common with one treatment approach than another.

Tell your doctor about any heart conditions, high blood pressure, diabetes, kidney problems, or other health conditions, as these may affect treatment choices and monitoring

Ask the Doctor:

- Given my health history and how long I may stay on this treatment, how will you monitor side effects?
- Could any of my other health conditions or medications change how you monitor me or whether this treatment remains the right option?
- What monitoring is specific to my current treatment approach?
- Are there things to consider to reduce or manage these risks?

5

Use this discussion to clarify which symptoms can wait until your next visit and which symptoms should be reported sooner.

A side effects table can help you ask which side effects are common, serious, or likely to affect daily life, but your doctor should help you interpret what matters for your own treatment.

Ask the Doctor:

- Which symptoms or side effects should I report right away?
- Which symptoms can wait until my next appointment?
- Which symptoms would mean I should seek urgent medical care?