

## CLL FACTS

- Males are twice as likely to females to be diagnosed with CLL.
- Most patients will not need treatment until one or more indications are met.
- Some patients never need treatment. [Source]

## CLL RESOURCES

- [ACCC](#)
- [CancerCare](#)
- [Cancer Grace](#)
- [Family Reach](#)
- [CLL Society](#)
- [Cancer Support Community](#)
- [LLS](#)
- [Triage Cancer](#)
- [CLL Support \(UK based\)](#)
- [Leukemia Research Foundation](#)

## COMMON CLL TREATMENT SIDE EFFECTS

- Risk of infections and cytopenia
- If you are on a BTK inhibitor: heart palpitations/arrhythmias & hypertension (high blood pressure)
- If you are on a venetoclax-based (Venclexta) therapy: tumor lysis syndrome (TLS), which may require monitoring in the hospital [Source]

## MANAGING SYMPTOMS FROM CLL TREATMENTS

- Bring a list of all medications to your healthcare team (including over-the-counter meds and supplements) so it can be reviewed ahead of starting treatment. In some cases, there are interactions of medications, or they can have overlapping side effects/risks.
- Work with your healthcare team (which includes your pharmacist, nurse coordinator, patient educator, triage nurse, etc.) and care partner to make a treatment management plan.
- Antibiotics or myeloid growth factors may be given to treat neutropenia.
- Be aware your healthcare team may recommend starting other new medications to help with the risks of treatment (i.e., to lower uric acid or risk of TLS), antiviral drugs to try to prevent virus reactivation during treatments, and in some cases, a short course of antibiotics as prevention if the neutrophils are low.
- Extra fluid via IV or certain medications can be used to prevent TLS if your risk is high (i.e., if you have reduced renal function, aren't able to take in enough fluids, etc.).
- Blood transfusions may be required to support you as you start CLL treatment.
- Some treatments like BTK inhibitors have a risk for easy bleeding so be sure to tell your healthcare team of any planned surgeries/procedures. You may be instructed to pause CLL treatment before and after the surgery/procedure.
- Do not take any anti-inflammatory pain medications (these can cause bleeding problems) unless your healthcare provider tells you to use them.
- Take medicine for diarrhea only if and as prescribed. Ask your healthcare provider how much or how long diarrhea should last before calling to report it.
- With a weakened immune system, take steps to minimize infections. Talk to your team about which vaccines you, as an immunocompromised individual, should take. This includes asking about both needed vaccines **and** avoiding live/attenuated vaccines due to risk of reactivation.
- Keep up-to-date with other health maintenance appointments, such as skin/dermatological exams and other standard cancer screenings, as CLL brings a higher risk of secondary malignancies.

[Source, Source, Source, Source, Source]

## CLL EXPERT TIPS

**START HERE TIP:** "It's okay to feel overwhelmed with information during your first appointment. Recognize you can take this self-education in steps since this is a long journey (yours could include watch and wait, never needing treatment, switching treatments due to symptoms, etc.)" - Dr. Danielle Brander

**START HERE TIP:** "Make a list of prioritized questions to ask your healthcare team and bring someone to be your ears for the appointment and take notes, because it's very easy in the moment to forget what questions you might want to ask or what is being said." - Dr. Danielle Brander

**START HERE TIP:** "Don't be afraid to visit and get more information from another blood cancer expert or CLL/lymphoma expert clinic, particularly around treatment, clinical trials, and symptom management. It doesn't mean you're changing who your core care team could be. These visits can be an extra step to help you understand or hear things in a different way." - Dr. Danielle Brander

This **START HERE CLL** program resource guide is brought to you by the **Patient Empowerment Network**.

It is made possible through support from Janssen Oncology, Inc., Pharmacyclics, an AbbVie Company, Merck and generous donations from people like you.