

CLL (Chronic Lymphocytic Leukemia) Toolkit

We have collected advice & tips from Belongers diagnosed with CLL to help you during your journey.

Facing A New CLL Diagnosis

- ❖ Know whom to call and keep the information of the healthcare team who you can contact with any questions or concerns.
- ❖ Prepare and write down questions before your appointments, take written notes with the specialist answers.
- ❖ Do not be afraid to ask repeated questions at each appointment.
- ❖ Have someone with you at appointments.
- ❖ Understand the treatment approach and the reasoning for it. If treatment is a consideration, ask for more information about the opportunity to participate in a clinical trial.
- ❖ Consider a second opinion from a CLL specialist.
- ❖ It is essential to understand that Watch & Wait is considered a treatment option if you don't need to treat the CLL at that time.

For people diagnosed with CLL who have minimal changes in their blood counts and no symptoms, the current standard of care is the watch-and-wait or “active surveillance” approach.

Regular medical examinations and blood work is done to determine whether the disease is stable or beginning to progress.

This approach may be concerning for people who are diagnosed with CLL.

Studies comparing the watch-and-wait approach to an early treatment approach find no benefits for treating people with low-risk CLL. Treatment will be given if symptoms worsen or based on factors that indicate the progression of the disease.

Contact your medical team if the symptoms worsen or start impacting your quality of life.

Questions to Ask About Diagnosis and Treatment:

- ❖ Is the CLL fast- or slow-growing?
- ❖ What were the results of the genetic tests? What impact will these results have on the treatment and prognosis?
- ❖ When will treatment start?
- ❖ What are the treatment options? What are the benefits and risks of each option?
- ❖ What are all the symptoms I should be aware of that may indicate disease progression?
- ❖ Does my age, health, and other factors affect the treatment options?
- ❖ Is it safe to have vaccinations with the condition? Are there vaccinations I should not have?
- ❖ How can I relieve or prevent the side effects of treatment?
- ❖ Am I allowed to take dietary and natural supplements?

The more you know about your CLL diagnosis, the better prepared you will be to make informed decisions. Remember, CLL looks different from one individual to another. This is your personal journey.

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