# Understanding Chronic Lymphocytic Leukemia (CLL)

## A Patient Guide to Diagnosis, Treatment, and Monitoring

### What Is CLL?

Chronic lymphocytic leukemia, or CLL, is a slow-growing cancer of the blood and bone marrow. Hearing this diagnosis can feel overwhelming. But it may help to know that CLL is one of the most common types of leukemia in adults, and that today, people are living longer than they did in the past.

Every person's journey with CLL is different. Some people never need treatment. Some need it soon after diagnosis. Others may need it later.

You might hear two different names for this disease: CLL and SLL (small lymphocytic lymphoma) are the same disease. It's usually called CLL when most cancer cells are in the blood and bone marrow, and SLL when most are in the lymph nodes.

### How Is CLL Diagnosed?

CLL is often found during a routine blood test, before symptoms begin. A complete blood count, or CBC, measures the number of different blood cells. It may show a high number of lymphocytes, a type of white blood cell.

If the lymphocyte count is high, your provider may order flow cytometry. This test looks closely at the cells in your blood to check for CLL. CLL can usually be diagnosed with blood tests. Sometimes other tests, such as a bone marrow or lymph node biopsy, are needed.

### What Stage Is My CLL?

CLL stage is based on your test results. Your care team will explain your stage and what it means for you. *Early stage:* You have a high lymphocyte count, but your lymph nodes, spleen, and liver



are a normal size. *Intermediate stage:* You have a high lymphocyte count and enlarged lymph nodes, spleen, or liver. Your red blood cell and platelet counts are normal. *Advanced stage:* CLL is also affecting your blood counts. This can cause anemia, a low red blood cell count, which can make you feel very tired, or thrombocytopenia, a low platelet count. This can make it harder for your blood to clot.

### What Genetic Tests Do I Need?

Your care team may also order genetic tests on your blood or biopsy sample. These tests look for changes that can affect your treatment plan. They may be repeated before starting a new treatment as well. Some changes have names like TP53 or del(17p). Other tests look at a genetic marker called IGHV, which can show how your CLL may behave over time. This information helps your care team find treatments that may work better for you.

### How Will I Know if I Need Treatment?

When you first find out you have CLL, you usually don't need to start any treatment right away. Instead, your care team may use a plan called "active observation." This approach is also called "watch and wait."

If you feel fine, your care team will keep a close eye on your regular blood tests. It's normal to notice when a test number changes. One number going up or down does not mean you need treatment right away. Your care team looks at the pattern over time—that's what matters most.

Your care team may start treatment if they see changes, such as:

- Your white blood cell count rising quickly over time
- Your red blood cell or platelet counts dropping
- Your lymph nodes or spleen swelling or getting bigger
- New or worsening symptoms, fevers without an infection, drenching night sweats, losing weight without trying, or severe tiredness

### How Is CLL Treated?

Treatment for CLL has changed. In the past, chemotherapy was often used first. Today, treatment has moved toward targeted therapies.

*Chemotherapy* kills fast-growing cells or stops them from dividing. *Targeted therapy* acts on specific proteins or signals that CLL cells use to grow and survive.

For CLL, there are three main types of targeted therapy: BTK inhibitors, BCL2 inhibitors, and anti-CD20 therapies. These treatments work in different ways. Your care team can explain which types may be options for you. See the table on p. 3 for a short explanation.

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# Michael's Journey



Michael is a 74-year-old retired mechanic who was used to having a bit of grease on his hands and an ache in his back. More than 10 years ago, he noticed he had started feeling very tired all the time. He would wake up sweating at night and noticed painless, swollen lumps in his neck. His primary care provider ordered some blood tests. The results led to more testing, which showed that Michael had CLL.

At that time, chemotherapy was used more often for CLL. When he needed treatment, his care team recommended chemotherapy. At first, Michael was very scared by the word "leukemia," but his provider explained that CLL is a blood cancer that often grows slowly. He went through a course of chemotherapy. After treatment, his care team continued regular checkups. Michael spent his days restoring a classic car in the garage.

## CLL Becomes Active Again

Years later, Michael again felt very tired. He also lost weight without trying and had pneumonia that took weeks to go away. His blood tests and symptoms showed that his CLL had become active again.

## A New Medicine

Michael and his care team reviewed his health, test results, previous treatment, and goals. Together, they chose a BTK inhibitor, a type of targeted therapy taken as a pill. He and the care team talked about what to expect and when to call. He added the pill to his morning routine with his coffee and newspaper. At each visit, they reviewed any changes in how he felt, his blood test results, and whether the treatment still fit his needs. His team understood one of his priorities: getting back to working on his car.

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## Michael's Advice to People Newly Diagnosed With CLL

If Michael could sit down with someone who just found out they have CLL, here is what he would say:

- **Take a deep breath:** "Leukemia is a scary word, but CLL is often treated more like managing a chronic illness. Treatment for CLL has changed a lot in the past 10 years."
- **Speak up:** "Don't try to tough out your symptoms or side effects. If something feels off, tell your care team right away so they can help adjust your care."
- **Keep living and doing what you enjoy:** "Cancer is just one part of my life, but it isn't my whole life. Keep doing the things that bring you joy."

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## How Will We Choose a Treatment?

Treatment decisions may change over time. You and your care team will discuss your test results, overall health, other medicines, previous treatments, and the side effects, schedule, and length of each option. Tell them what matters to you, such as continuing to work, taking pills at home, limiting clinic visits, or having a planned end date. More than one option may be reasonable. You and your care team can choose a plan together and revisit it as your needs change.

| Class | How It Works | How It's Given |
|---|---|---|
| BTK inhibitors | Blocks a signal (BTK) that CLL cells need to grow | A pill taken at home |
| BCL2 inhibitors | Blocks a protein (BCL2) that helps CLL cells survive | A pill taken at home |
| Anti-CD20 therapies | Attaches to CD20, a marker on CLL cells | Usually given by IV at a clinic |

## How Long Will My Treatment Last?

Some CLL treatments have no planned stop date. This is called *continuous therapy*. Other treatments are given for a set amount of time. This is called *fixed-duration therapy*. When treatment ends, regular checkups continue. Your test results, overall health, previous treatment, and preferences help determine which options may be right for you.

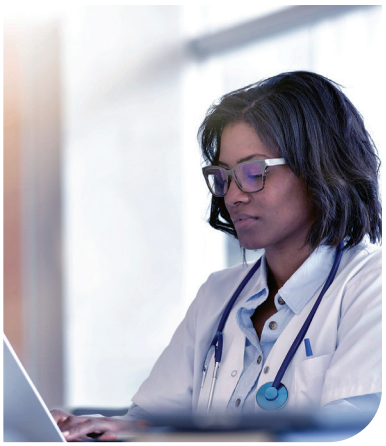
### Two Ways CLL Treatment May Be Planned

**Continuous Therapy**

- Treatment starts
- Treatment and regular checkups
- No planned stop date

**Fixed-Duration Therapy**

- Treatment starts
- Treatment for a set time
- Treatment ends
- Checkups continue



## Side Effects: Speak Up Early

All CLL treatments can cause side effects, and each person may react differently. Before starting treatment, ask what changes to watch for and which ones require a quick call. During treatment, tell your care team about any new or worsening symptom, even if it seems small. Do not stop or change your medicine on your own. Your care team can tell you what to do next.

## Questions to Ask Your Care Team

**Understanding My CLL**

- What stage is my CLL?
- What do my blood test results show, and what changes in my blood tests are important?
- Which genetic tests do I need, and what will the results tell us?
- How long will it take to get my test results?

**Before Starting or Changing Treatment**
*(bring these anytime you and your care team are considering* a new step — at diagnosis or later)

- Do I need to start treatment now, or can I wait?
- Do we need all my test results before choosing treatment?
- How often will I need office visits and blood tests?

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- Will my treatment be a pill, an IV, or both?
- What should I do if I miss a dose?
- How long is my treatment planned to last?
- How will we know if my treatment is working?
- What can you tell me about clinical trials?

### Staying Safe & Well

- What side effects should I watch for?
- When should I call my care team?
- What should I do if I get a fever or feel sick?
- Are there vaccines I should get or vaccines I should avoid?
- How can I lower my risk of infection?
- Are there any changes I should make to my diet or lifestyle?
- Should I continue to see my other usual providers and specialists?

### Making Decisions Together

Shared decision-making means you and your care team make treatment choices together. It continues over time. Revisit when your health, CLL, or priorities change.

Before you decide, make sure you:

- Understand all of your treatment choices
- Understand what active observation or treatment would involve
- Talk about the benefits and possible side effects of each therapy
- Pick the treatment that fits your goals and what matters most to you

## Build Your Support Team

Ask someone you trust to come to appointments, take notes, help with transportation, or remind you about medicines. Tell your care team if you need more support.

CLL treatment looks very different than it did 10 years ago. Many of today's options were made possible in part by people who took part in clinical trials. Their participation helped researchers learn more and improve care for others.

## Resources for Patients

**Chronic Lymphocytic Leukemia (CLL) Society**
*cllsociety.org*

**Lymphoma Research Foundation (LRF)**
*lymphoma.org*

**Association of Cancer Care Centers (ACCC)**
*www.accc-cancer.org*

**CancerCare®**
*Cancercare.org*

**myTRIAList**
*myTRIAList.org*

**Blood Cancer United: Clinical Trial Support Center**
*bloodcancerunited.org*

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