

Preparing for Your Visit for Chronic Lymphocytic Leukemia (CLL)

You have been referred to Huntsman Cancer Institute because you have been diagnosed with chronic lymphocytic leukemia (CLL). This factsheet provides information about CLL, tells you what to expect during your visit, introduces your treatment team, and connects you to resources. Please take some time to review this information before your visit.

Where can I find information about CLL?

To help you understand your disease better, we have sent a copy of *Chronic Lymphocytic Leukemia* by the Leukemia and Lymphoma Society. If you did not receive your copy, please call our clinic.

What is CLL?

CLL is a chronic and slow-growing type of blood cancer. It affects a specific type of white blood cell called a B lymphocyte. White blood cells fight infection as an important part of your body's immune system. Normally, B lymphocytes do their job and die off when they should.

In CLL, an abnormal B lymphocyte cell develops. These cells build up in the body and lose their signal to die off when they should. The cells can build up in the bone marrow, blood, lymph nodes, and other organs.

These CLL cells can affect your body's ability to produce healthy red blood cells and platelets. This makes it difficult for your blood to transport oxygen around your body or form a clot if you start bleeding.

Currently, there is no cure for CLL, but we have excellent treatment options. Many are targeted therapies that you can take by mouth.

Most patients with CLL will NOT require treatment at the time of diagnosis. This is because:

- Many studies have shown that there is no benefit to early treatment of low-risk patients without symptoms.
- Our goal is to keep you feeling as well as possible for as long as possible. We don't want to make you feel worse by giving you a treatment you don't really need.

When do we treat CLL?

You may need treatment for CLL sooner if:

- You have anemia (a low red blood cell count) with a hemoglobin of less than 11 and no other identifiable cause.
- You have clinically significant low platelets of less than 100.
- You have symptoms that we think are from CLL and no other identifiable cause:
 - Severe fatigue that keeps you from carrying out your normal daily activities.
 - Unexplained fevers.
 - Drenching night sweats.
 - Unplanned weight loss (more than 10% of your body weight in less than 6 months).
 - Enlarged lymph nodes that are causing you symptoms.
 - An enlarged spleen that is causing you symptoms.

If you do not need treatment right away, your doctor may recommend a "watch and wait" approach. During this time, your provider will see you every 3-6 months for blood counts, a physical exam, and a review of your symptoms.

What can I expect during my visit?

Before your appointment, please visit our website, huntsmancancer.org/patientservices, for information about directions, parking, items you should bring, and visitor policies.

We will let you know if you are able to have a visitor come with you. If you are not able to bring someone with you, we encourage you to have a friend or family member on a speaker or video call so that they can listen in during your visit.

Our team will ask about your medical history, current medications, and how you have been feeling recently. We will also talk about cancer screenings and vaccinations.

We will perform a basic physical exam.

Our team will talk about tests and what they might mean for your treatment.

We stage CLL differently than other types of cancers. Because it is a cancer of blood cells, it can go anywhere your blood goes. We use a staging system called the Rai stage. We will review your disease stage at your visit.

We may also talk about research studies that can help us develop new treatments for CLL. You will always have a choice whether or not to participate in research. It will not change how we care for you.

We may ask you about something called tissue banking. This is when we draw a few extra tubes of blood while you are already having blood drawn. We use these samples to study your CLL cells and develop new therapies for CLL. One of our study coordinators will discuss this with you in greater detail. You must sign an informed consent for us to obtain samples from you.

You will have blood drawn after your visit.

After your blood results come back, we will call you to talk about the results.

Some important tests we refer to as prognostic markers. We will look at the chromosomes in your CLL cells and look for other gene mutations that will help us determine how your CLL will behave. These test results take several weeks to come back. We will call you to discuss what they will mean for you.

What can I expect during a virtual visit?

Our team will work with you to make sure our visit functions well and protects your privacy.

Virtual visits are nearly identical to an in-person visit, but we will not be able to perform the physical exam. For labs, we will send orders to have blood drawn at a location close to you.

Who will I see during my visit?

Members of your care team may include:

- Doctors
- APCs (physician's assistants and nurse practitioners)
- Nurses
- Medical assistants
- Pharmacists

You may also see medical students, residents, and fellows during your visits.

What if I have more questions?

Contact your cancer care team via MyChart or call

In an emergency, call 911 or go to your closest emergency department.

You can send us a message through MyChart, and you will generally hear back from us within one business day. If you have not already, we encourage you to sign up for MyChart at mychart.med.utah.edu.

Where can I find other resources?

We want to make sure you are getting information on CLL from good sources.

- Be sure to visit HCI's website to help prepare for your visit.
- Here are some of our favorite websites:
 - The CLL Society: (cllsociety.org)
This group was formed by a family physician who has had CLL for many years.
 - The Leukemia & Lymphoma Society: (lls.org)
 - The Lymphoma Research Foundation: (lymphoma.org)

You can also visit the G. Mitchell Morris Cancer Learning Center on the 6th floor of Huntsman Cancer Hospital South or contact their cancer information specialists for more information, books, and personalized resources. Call 888-424-2100 or visit huntsmancancer.org/clc.