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EASY READING

If You Have Chronic Lymphocytic Leukemia (CLL)

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What is leukemia?

Cancer can start any place in the body. Leukemia starts in the **bone marrow**, the soft inner part of certain bones where new blood cells are made. It starts when certain blood cells grow out of control and crowd out normal blood cells. This makes it hard for the body to work the way it should.

There are many types of leukemia. Most are named based on if they're fast growing (acute), or slower growing (chronic). They are also named by the type of bone marrow cell (myeloid or lymphocytic) the leukemia starts in.

What is chronic lymphocytic leukemia (CLL)?

Chronic lymphocytic leukemia, or **CLL** for short, is cancer that starts in early forms of white blood cells called **lymphocytes** in the bone marrow. When they work right, lymphocytes help the body fight infections.

In CLL, the leukemia cells grow out of control and crowd out normal blood cells. These cells often build up slowly over time. Many people don't have any symptoms for at least a few years. In time, the cells can spread to other parts of the body, including the lymph nodes, liver, and spleen.

Different types of CLL

There are two kinds of CLL. One kind grows very slowly and it may take a long time before treatment is needed. The other kind grows faster and is more serious leukemia. Ask your doctor which kind you have.

Questions to ask the doctor

- Why do you think I have leukemia?
- Is there a chance I don't have leukemia?
- Would you please write down the kind of leukemia you think I might have?
- What will happen next?

How does the doctor know I have CLL?

The doctor will ask you questions about your health and do a physical exam. Many people with CLL don't have any symptoms. It's often found when the doctor orders blood tests for some other health problem or during a check-up. Some signs of CLL include:

- Feeling weak or tired
- Losing weight
- Fevers, or sweating a lot at night

Tests that may be done

If signs are pointing to CLL, more tests will be done. Here are some of the tests you may need:

Blood cell counts: This blood test is often the first test done. Most people with CLL have too many lymphocytes in their blood and not enough of other types of blood cells.

Bone marrow aspiration and biopsy: Blood tests can most of the time tell the doctor if you have CLL, but testing the bone marrow is helpful to tell how bad it is. A doctor uses thin, hollow needles to take out small amounts of bone marrow, usually from the back of your hip bone. The bone is numbed, and you may be given a drug to make you sleepy during the test. The samples are sent to a lab to see if there are leukemia cells in the bone marrow.

Lab tests for leukemia: Samples from your blood, bone marrow, or lymph nodes are looked at under a microscope (and other tests might be done on them) to help the doctor find out what kind of leukemia you have.

Other blood tests: If you do have leukemia, other blood tests will be done to see how well your liver, kidneys, and other organs are working.

CT scan: CT scans (also called CAT scans) use x-rays to make pictures of the inside of your body. This test can help tell if the leukemia has spread into lymph nodes in your chest or to organs like your spleen or liver.

Questions to ask the doctor

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

How serious is my CLL?

If you have CLL, the doctor will want to find out how far it has spread. This is called staging.

The stage of CLL describes its growth or spread to other parts of your body, including the lymph nodes, liver, and spleen. Be sure to ask the doctor about the stage of your CLL and what it means for you.

Questions to ask the doctor

- Does anything about my cells change the treatment? Or make my case better or worse?
- Are there other doctors I need to see?
- How many people with this type of leukemia have you treated?
- Do you know the stage of my leukemia? If not, how and when will you find out the stage?
- Would you explain what the stage means in my case?
- Based on the stage of the leukemia, how long do you think I'll live?
- What will happen next?

What kind of treatment will I need?

CLL often grows slowly, so you might not need to be treated right away. Your CLL might just be watched closely instead. If you do need treatment, the most common kinds of treatment for CLL are:

- Chemotherapy
- Monoclonal antibodies
- Targeted therapy

Sometimes you may also need other kinds of care to help treat infections or low blood cell counts.

Treatment is given for a time to improve symptoms caused by CLL. Then you may be off treatment and watched closely. If symptoms get worse again, more treatment can be given.

The timing and treatment plan that's best for you depends on:

- The type of CLL you have
- If the CLL is causing you symptoms or other problems
- The chance that a certain type of treatment will help treat the CLL
- Your age and overall health
- Your feelings about the treatment and the side effects that might come with it

Chemo

Chemotherapy, or chemo, is the use of drugs to kill cancer cells. This is one of the main treatments for CLL.

Most of the time the drugs are given either into a vein or as pills. Once the drugs enter your blood, they go through your whole body. Doctors give chemo in cycles, with each cycle followed by a rest period. Chemo cycles last about 3 to 4 weeks. Many kinds of chemo drugs are used to treat CLL. Ask your doctor which drugs you'll get.

Side effects of chemo

Chemo can have a lot of [side effects](#)¹ like:

- Hair loss
- Mouth sores
- Not feeling like eating
- Feeling sick to your stomach and throwing up
- A greater risk of infections
- Getting black and blue marks and bleeding easily
- Tiredness

But these problems tend to go away after treatment ends. There are ways to treat most chemo side effects. Be sure to talk to your cancer care team so they can help.

Monoclonal antibodies

Monoclonal antibodies are man-made versions of immune system proteins (antibodies) that attach to a certain place on CLL cells. They can help kill the cells or tell them to die.

These drugs are given into a vein. They can be given alone or along with chemo. There are different kinds of these drugs. Each one can cause different side effects, so ask your doctor what you can expect.

Targeted therapy

Targeted drugs are newer treatments used for CLL. These drugs affect mainly CLL cells and not normal cells in the body. They may work even if other treatment doesn't. They often come as pills that you can take at home. These drugs have different side effects from chemo, and they're often not as bad.

Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

Clinical trials are one way to get the newest cancer treatment. They're the best way for doctors to find better ways to treat cancer. If there's one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital takes part in conducts clinical trials. See [Clinical Trials²](#) to learn more.

What about other treatments that I hear about?

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be vitamins, herbs, special diets, and other things. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

Questions to ask the doctor

- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the CLL?
- Will I need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about these side effects?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets I hear about? How will I know if they're safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

What will happen after treatment?

If you have CLL, there might be times when you're not being treated, but you will still need to see your cancer doctor. Be sure to go to all of your follow-up visits. You will have exams, blood tests, and maybe other tests to see if the CLL is growing.

Having CLL and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to feel better.

You can't change the fact that you have CLL. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html
2. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
3. <http://www.cancer.org>

Words to know

Biopsy (BY-op-see): taking out a small piece of tissue to see if there are cancer cells in it.

Bone marrow aspiration and biopsy (ASP-er-AY-shun and BY-op-see): A procedure in which a thin, hollow needle is put into the center of a bone, usually the back of the hip bone, to take out a small amount of bone marrow so that it can be looked at under a microscope.

Bone marrow: The soft, spongy tissue in the hollow middle of certain bones of the body. This is where new blood cells are made.

Granulocyte (GRAN-you-lo-site): A type of white blood cell that helps the body fight infection.

Leukemia (loo-KEY-me-uh): Cancer of the blood or blood-forming organs.

Lymph nodes (limf nodes): Small, bean-shaped sacs of immune system tissue found all over the body and connected by lymph vessels; also called lymph glands.

Lymphocyte (LIM-fo-site): A type of white blood cell that helps the body fight infection.

Monocyte (MAH-noh-site): A type of white blood cell that helps the body fight infection.

Monoclonal antibodies (MA-nuh-KLO-nuhl AN-tih-BAH-dees): Man-made versions of immune system proteins (antibodies) that are intended to attach to a certain place on cancer cells. They can help kill the cancer cells or signal them to die.

Platelets (PLATE-lets): Parts of blood cells that help stop bleeding by plugging up holes in blood vessels after an injury.

White blood cells (WBCs): Blood cells that help defend the body against infections. There are many types of white blood cells.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (<http://www.cancer.org>)³. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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