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EASY READING

If You Have Acute Lymphocytic Leukemia (ALL)

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What is leukemia?

[Cancer](#)¹ starts when cells in a part of the body begin to grow out of control. There are many kinds of cancer.

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 (usually white 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](#)². Some are rare. Most are named based on if they are fast-growing (acute), or slower-growing (chronic). They are also named by which type of bone marrow cell (myeloid or lymphocytic) the leukemia starts in.

What is acute lymphocytic leukemia (ALL)?

Acute lymphocytic leukemia (ALL) is also called **acute lymphoblastic leukemia**. ALL starts from early forms of lymphocytes, a type of white blood cell.

ALL grows quickly. The leukemia cells soon enter the blood and can sometimes spread to the lymph nodes, liver, spleen, central nervous system (brain and spinal cord), and other organs.

Are there different types of ALL?

There are different [subtypes of ALL](#)³. In some of these, the ALL cells have gene changes that can affect how well treatment works. Your doctor can tell you more about the kind of ALL 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 ALL?

Most [signs and symptoms of ALL](#)⁴ are from low numbers of blood cells. You may feel tired, weak, dizzy and have a fever. You may also lose weight or have bone or joint pain, and might bruise or bleed easily.

Your doctor will ask you questions about your health and look for swollen lymph nodes, swelling in the belly, or signs of bleeding, bruising, or infection.

Tests that may be done

If the doctor suspects leukemia, here are some of the [tests](#)⁵ you may need:

Blood cell counts: This blood test is often the first test done. Most people with ALL have too many white blood cells (mostly early forms called **blasts**) and not enough of other types of blood cells.

Bone marrow aspiration and biopsy: For these tests, a doctor uses thin, hollow needles to take out small amounts of bone marrow, most often from the hip bone. The

area around the bone is numbed, and you may be given a drug to make you sleep during the test. The samples are sent to a lab to see if there are leukemia cells in the bone marrow. If you are already being treated, these tests can be used to see how well treatment is working.

Spinal tap (lumbar puncture): For this test, the doctor first numbs an area in the lower part of the back over the spine. A small, hollow needle is placed between the bones of the spine to draw out some of the fluid (called CSF) from around the brain and spinal cord, which is then checked for leukemia cells.

Lab tests for leukemia: Samples from blood, bone marrow, or CSF are looked at under a microscope to help the doctor find out what kind of leukemia you have. If leukemia cells are found, other lab tests might be done on the cells to look for certain gene changes. The results of these tests might affect how your leukemia is treated.

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

Imaging tests: These tests take pictures of the inside of the body. There are many kinds of imaging tests, like x-rays and CT and MRI scans. They are sometimes done to look for leukemia, but more often they are done to look for infections or other problems. Ask your doctor what imaging tests you may need.

Questions to ask the doctor

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

Different types of ALL

There are many types of ALL. It is grouped into different kinds, based mainly on:

- The type of lymphocyte it starts in
- How early or mature the cells are
- The gene changes inside the ALL cells

Ask your doctor about the type of ALL you have. This can affect your outlook and which type of treatment might be best for you.

Questions to ask the doctor

- What type of ALL do I have?
- Are there any factors that might affect my chances of getting better??
- Are there other doctors I need to see?
- How many people with ALL have you treated?
- What will happen next?

What kind of treatment will I need?

ALL often grows quickly, so it's important to start treatment as soon as you can after it is found.

The most common treatment for ALL is chemotherapy (chemo), which most people get for at least 2 years. Other treatments are used less often.

The treatment plan that is best for you will depend on:

- The type of ALL
- If the ALL cells have changes in certain genes
- The chance that a type of treatment will cure the leukemia or help in some way
- Your age and overall health
- Your feelings about the treatment and the side effects that come with it

Chemo

[Chemo](#)⁶ is the use of drugs to fight cancer. These drugs go into the blood and spread all over the body. Most chemo drugs don't reach the area around the brain and spinal cord, so the drugs may also need to be put right into the CSF to kill cancer cells there. Chemo is given in cycles or rounds. Each round of treatment is followed by a break.

ALL treatment usually has 3 phases:

- The first phase is called **induction**. Its goal is to clear the blood of all leukemia cells. You usually get 3 or more chemo drugs over a month or so, and you might need to spend some of this time in the hospital.
- The second phase is called **consolidation**. Its goal is to kill any leftover leukemia cells and keep the ALL from [coming back](#)⁷. This treatment is often given over several months. Sometimes it may include a stem cell transplant (see below).
- The third phase is called **maintenance**, which is done to help keep the ALL from coming back. It uses lower doses of chemo drugs given over about 2 years.

People whose ALL cells have a certain gene change are often given a targeted drug (see below) along with chemo for their treatment.

Side effects of chemo

Chemo can have many side effects, like:

- Hair loss
- Mouth sores
- Not feeling like eating
- Diarrhea
- Being sick to your stomach and throwing up
- More 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.

Stem cell transplant

A [stem cell transplant \(SCT\)](#)⁸ lets doctors use very high doses of chemo to kill the leukemia cells. The high doses of these drugs destroy the bone marrow, which keeps new blood cells from being made. Although the drugs destroy the bone marrow, stem cells given after the chemo can bring back the blood-making bone marrow stem cells. There are different kinds of SCT, each of which can have bad side effects. Ask your doctor which type you will have and what to expect.

Targeted therapy drugs

[Targeted drugs](#)⁹ are not the same as chemo because these drugs mainly go after cancer cells, not normal cells. Sometimes ALL cells have certain gene changes, and targeted drugs can help treat these leukemias. Ask your doctor which drug you will get, and what the side effects might be.

Immunotherapy

[Immunotherapy](#)¹⁰ helps a person's own immune system find and destroy leukemia cells. This type of treatment can help some people with ALL, often after other treatments have been tried. Ask your doctor about this type of treatment, and what the side effects might be.

Surgery

[Surgery](#)¹¹ has only a small role in treating ALL. Surgery may be used before chemo to put a small plastic tube called a **central venous catheter** (CVC) into a large vein. This allows drugs such as chemo to be given and blood samples to be taken out.

Radiation treatments

[Radiation](#)¹² uses high-energy rays (like x-rays) to kill cancer cells. This treatment may be used to kill any leukemia cells that may be hiding in the brain or in the testicles (in men). It also can be used before a stem cell transplant. Ask your doctor if radiation will be part of the treatment and what to expect.

Side effects of radiation treatments

Side effects depend on where the radiation is aimed. The most common side effects of radiation are:

- Skin changes where the radiation is given
- Feeling very tired

These side effects tend to get better after treatment ends. Radiation can also cause long-term effects if it is aimed at the brain, heart, lungs, or other body parts. Talk to your cancer care team about what to expect.

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.

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 conducts clinical trials. See [Clinical Trials](#)¹³ to learn more.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find 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.

What about other treatments I hear about?

When you have cancer you may hear about [other ways to treat the cancer or treat your symptoms](#)¹⁴. 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 leukemia?
- Should we think about a stem cell transplant? If so, when?
- How long do you think I'll live?
- What will we do if the treatment doesn't work or if the leukemia comes back?
- What side effects could I have from treatment?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are 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?

Treatment for ALL for most people lasts about 2 years. Even after treatment ends, you will need frequent [follow-up exams](#)¹⁵ – probably every few months for several years. Be sure to go to all of these follow-up visits. Your doctors will ask about symptoms, do physical exams, and order blood tests and maybe other tests to see if your leukemia has come back.

Having ALL 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 ALL. 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/cancer/cancer-basics/what-is-cancer.html
2. www.cancer.org/cancer/acute-lymphocytic-leukemia/about/what-is-all.html
3. www.cancer.org/cancer/acute-lymphocytic-leukemia/detection-diagnosis-staging/how-classified.html
4. www.cancer.org/cancer/acute-lymphocytic-leukemia/detection-diagnosis-staging/signs-symptoms.html
5. www.cancer.org/cancer/acute-lymphocytic-leukemia/detection-diagnosis-staging/how-diagnosed.html
6. www.cancer.org/cancer/acute-lymphocytic-leukemia/treating/chemotherapy.html
7. www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html
8. www.cancer.org/cancer/acute-lymphocytic-leukemia/treating/bone-marrow-stem-cell.html
9. www.cancer.org/cancer/acute-lymphocytic-leukemia/treating/targeted-therapy.html
10. www.cancer.org/cancer/acute-lymphocytic-leukemia/treating/monoclonal-antibodies.html
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12. www.cancer.org/cancer/acute-lymphocytic-leukemia/treating/radiation-therapy.html
13. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
14. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html

15. www.cancer.org/cancer/acute-lymphocytic-leukemia/after-treatment/follow-up.html
16. <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: The soft, spongy tissue in the middle of certain bones of the body. This is where new blood cells are made (and where leukemia starts).

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

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

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

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

Red blood cells (RBCs): Blood cells that carry oxygen from the lungs to all other tissues of the body and take carbon dioxide back to the lungs to be removed.

Stem cell transplant: A treatment that replaces blood-forming stem cells in the bone marrow with new stem cells that come from the bone marrow of either the patient or a donor.

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>)¹⁶. 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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