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EASY READING

If Your Child Has Leukemia

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What is childhood leukemia?

Cancer can start any place in the body. Leukemia is a type of cancer that starts in the **bone marrow**, the soft inner part of certain bones where new blood cells are made. Most leukemias start in white blood cells. When the white blood cells grow out of control and crowd out normal blood cells, it makes it hard for the body to work the way it should. The leukemia cells quickly spread to the blood and from there to other parts of the body.

Normal blood cells made in bone marrow

To understand the different types of leukemia, it helps to know about the types of blood cells.

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

White blood cells (WBCs) help the body fight infections. There are many types of white blood cells, but the main types are:

- Lymphocytes
- Granulocytes
- Monocytes

Most leukemias start in early forms of white blood cells.

Platelets are actually pieces that break off from certain bone marrow cells. Platelets help stop bleeding by plugging holes in blood vessels caused by cuts or bruises.

Types of leukemia in children

There are many [types of leukemia](#)¹, which can be either fast growing (acute), or slower growing (chronic). Almost all leukemia in children is acute. Acute leukemias can progress quickly, so they need to be treated right away. Your doctor can tell you more about the type your child has. Below are the medical names for the 2 most common types of leukemia in children.

Acute lymphocytic leukemia (ALL)

Another name for ALL is acute lymphoblastic leukemia. This is the most common kind of childhood leukemia. It starts from the early forms of lymphocytes in the bone marrow.

Acute myeloid leukemia (AML)

Another name for AML is acute myelogenous leukemia. This is the second most common kind. There are many types of AML, which starts from cells that form the other white blood cells (not lymphocytes), red blood cells, or platelets.

Questions to ask the doctor

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

How does the doctor know my child has leukemia?

Sometimes childhood leukemia can be mistaken for common illness like a cold or the flu, especially when [symptoms](#)² don't go away. Check with your child's doctor if your child has any of the following:

- Fever
- Feeling tired or weak
- Feeling cold or dizzy
- Pain in the bones
- Frequent infections
- Bruising or bleeding easily
- Headaches
- Stomach aches and poor appetite

The doctor will want to know how long your child has had these symptoms.

If signs are pointing to leukemia, more [tests](#)³ will be done. Here are some of the tests your child may need:

Blood cell counts: This blood test is often the first test done. Most children with leukemia have too many WBCs and not enough RBCs or platelets. The WBCs found are young blood cells called **blasts** that normally stay in the bone marrow until they are mature. Finding these blast cells in the blood, or finding very few WBCs at all, can also make the doctor think it is leukemia.

Bone marrow aspiration and biopsy: This test is usually needed to tell for sure if your child has leukemia. A doctor uses thin, hollow needles to remove small amounts of bone marrow, usually from the hip bone. The area around the bone is numbed, and the child may be given a drug to make them sleep during the test. The samples are sent to a lab to see if there are leukemia cells in the bone marrow.

This test can also be used later to see if the leukemia is getting better with treatment.

Spinal tap (lumbar puncture): This test is used to check for leukemia cells in the fluid around the brain and spinal cord (called CSF). The doctor first numbs an area in the lower part of the back over the spine. The doctor may give the child a drug to make them sleep during the test. A small hollow needle is placed between the bones of the spine to draw out some of the fluid, which is then sent to a lab.

Lab tests for leukemia: Many types of lab tests can be used to look at samples from blood, bone marrow, spinal fluid and lymph nodes. They can help the doctor tell if the child has leukemia, as well as find out what kind of leukemia it is.

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

Chest x-ray: A chest x-ray can help tell if organs or lymph nodes in the chest are swollen. It can also see if the child seems to have a lung infection.

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

MRI: This test also makes detailed pictures, but it's most helpful in looking at the brain and spinal cord.

Childhood leukemia subtypes

Leukemia does not have stages like most other cancers. The cancer starts in the bone marrow and quickly spreads to the blood, so leukemia cells are already throughout the body.

The most important concern for leukemia is figuring out the type (such as ALL or AML) and [subtype](#)⁴ of the leukemia. The subtype is based on things like:

- Which type of cell the leukemia started in
- If the leukemia cells have certain gene changes
- If the leukemia is the result of treatment for another cancer

Ask the doctor to explain what type and subtype of leukemia your child has. These help the doctor decide which treatment options are best.

Questions to ask the doctor

- Would you write down exactly what kind of leukemia my child has?
- Are there any factors that might affect my child's outlook?
- Are there other doctors we need to see?
- How much experience do you have treating this type of leukemia?
- What tests will my child need?

- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will we get the results?
- Who will explain the results?
- How soon do we need to start treatment?
- What will happen next?

What kind of treatment will my child need?

The treatment plan that's best for your child will depend on:

- The type and subtype of the leukemia
- The chance that a type of treatment will cure the leukemia or help in some way
- [Other factors](#)⁵, such as your child's age and certain lab test results
- Your feelings about the treatment and the side effects that could come with it

Chemo

[Chemotherapy](#)⁶, or chemo for short, is the use of drugs to kill cancer cells. This is the main treatment for most types of leukemia.

Usually the drugs are given into a vein, into the spine, or as pills. Once the drugs enter the blood, they spread throughout the body. Children might get more than one chemo drug at different times.

Doctors give chemo in cycles, with each cycle followed by a rest period. As a rule, AML treatment uses higher doses of chemo over a shorter time (usually less than a year), while ALL treatment uses lower doses over a longer time (about 2 to 3 years).

Side effects of chemo

Chemo can have many side effects, such as:

- Hair loss
- Mouth sores
- Loss of appetite

- Diarrhea
- Nausea and vomiting
- Increased risk of infections (because of low white blood cell counts)
- Bruising and bleeding easily (from low platelet counts)
- Tiredness (caused by low red blood cell counts)

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 child's cancer care team so they can help.

Targeted drugs

[Targeted drugs](#)⁷ are newer treatments that may be used for certain types of leukemia. These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatment doesn't. They might be injected into a vein, or they might come as pills that your child takes at home. These drugs have different side effects than chemo.

Immunotherapy

[Immunotherapy](#)⁸ helps the body's own immune system attack the leukemia. Some newer types of immune treatments, such as CAR T-cell therapy, are now being used for some hard-to-treat leukemias.

High-dose chemo and stem cell transplant

A [stem cell transplant \(SCT\)](#)⁹ can sometimes be used for children whose chances of cure are not as good with standard doses of chemo. SCT lets doctors use very high doses of chemo. These high doses destroy the bone marrow, which keeps new blood cells from being made. This poses a threat to the child's life. But after treatment is finished, the child gets a transplant of blood-forming stem cells to replace the bone marrow. There are different kinds of SCT, each of which can have serious side effects. Ask your doctor which type your child will have and what to expect.

Surgery

[Surgery](#)¹⁰ has only a small role in treating leukemia. This is because leukemia is a disease of blood and bone marrow and can't be cured with surgery. Surgery may be used before chemo to put a small plastic tube called a [central venous catheter \(CVC\) or venous access device \(VAD\)](#)¹¹ into a large vein. This allows drugs such as chemo to be given and blood samples to be taken without sticking a needle in each time.

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. It also can be used before a stem cell transplant. Ask your child's doctor if radiation will be part of the treatment and what to expect.

Side effects of radiation treatments

If your child's doctor suggests radiation treatment, talk about what [side effects](#)¹³ might happen. 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 organs. Talk to your child's 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 your child, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)¹⁴ 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 your child has, it's up to you whether to take part. And you can always stop at any time.

What about other treatments I hear about?

When your child has cancer you might hear about other ways to treat the cancer or its 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 child's 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 my child?
- What's the goal of this treatment? Do you think it could cure the leukemia?
- Will my child need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could my child have from these treatments?
- What can we do about side effects?
- Is there a clinical trial that might be right for my child?
- What about special vitamins or diets that friends tell me about? How will we know if they are safe?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- Is there anything we can do to help the treatment work better?
- What are our treatment choices?
- What do you recommend and why?
- Should we think about a stem cell transplant?
- What are the chances of curing the leukemia?
- What's the next step?

What will happen after treatment?

You'll be glad when treatment is over. But it's hard not to worry about the leukemia coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, your child will see your cancer doctor. Be sure they go to all of these follow-up visits. Your child will have exams, blood tests, and maybe other tests to see if the leukemia has come back.

At first, the doctor visits may be about once a month. Then, the longer your child is cancer-free, the less often the visits are needed.

With support from family, friends, other survivors, mental health professionals, and others, many children who survive leukemia can thrive in spite of the challenges they've

had to face.

Hyperlinks

1. www.cancer.org/cancer/leukemia-in-children/about/what-is-childhood-leukemia.html
2. www.cancer.org/cancer/leukemia-in-children/detection-diagnosis-staging/signs-and-symptoms.html
3. www.cancer.org/cancer/leukemia-in-children/detection-diagnosis-staging/how-diagnosed.html
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11. www.cancer.org/treatment/treatments-and-side-effects/planning-managing/tubes-lines-ports-catheters.html
12. www.cancer.org/cancer/leukemia-in-children/treating/radiation.html
13. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/radiation/effects-on-different-parts-of-body.html
14. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
15. <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 hip or breast 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.

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.

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

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>)¹⁵. 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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Written by

The American Cancer Society medical and editorial content team
(www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

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