



EASY READING

# If You Have Acute Myeloid Leukemia (AML)

## What is leukemia?

Cancer can start any place in the body. Leukemia (loo-KEY-me-uh) 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. 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 myeloid leukemia (AML)?

Acute myeloid leukemia (MY-uh-loid loo-KEY-me-uh), or *AML* for short, is a type of cancer that starts from cells in the bone marrow that are supposed to grow into different types of blood cells. Most often, AML starts in early forms of white blood cells.

AML is fast growing. The leukemia cells enter the blood quickly and sometimes can spread to the liver, spleen, central nervous system (brain and spinal cord), and testicles (in men).

## Are there different types of AML?

There are many subtypes of AML. In some of these, the AML cells have gene changes that can affect how well treatment works. Your doctor can tell you more about the kind of AML 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 AML?

Many people with AML have symptoms such as feeling tired or weak, losing weight, having a fever, sweating a lot at night, and loss of appetite.

The doctor will ask you questions about your health (including how long you have had symptoms) and do a physical and exam. If signs are pointing to AML, more tests will be done. Here are some of the tests you may need:

### Tests that may be done

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

**Bone marrow aspiration and biopsy** (ASP-er-AY-shun and BY-op-see): For these tests, a doctor uses thin, hollow needles to take small amounts of bone marrow, most of the time 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 having treatment, these tests can also be used to see how well treatment is working.

**Spinal tap (lumbar puncture):** This test is not often needed for people with AML. 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 that surrounds the brain and spinal cord, which is then checked for leukemia cells.

**Lab tests for leukemia:** Samples from blood, bone marrow, or spinal fluid 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 help the doctor know how best to treat your leukemia.

**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 your body. There are many kinds of imaging tests, like CT and MRI scans. They are sometimes done to look for infections or other problems rather than to look for the leukemia. 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?
- 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 is AML classified?**

AML is not just one disease. It really is a set of diseases that is grouped into different kinds, based mainly on:

- The type of cell from which the leukemia started
- How mature the cells are

Ask your doctor about the type of AML you have. This can affect your chances of getting better and which type of treatment might be best for you.

### **Questions to ask the doctor**

- Will you write down exactly what kind of leukemia I have?
- Are there any factors that might affect my chances of getting better?
- Are there other doctors I need to see?
- How many cases of AML have you treated?
- What type of AML do I have?
- What will happen next?

### **What kind of treatment will I need?**

AML often grows quickly, so it's important to start treatment as soon as possible after it is found.

The most common treatment for AML is chemotherapy (KEY-mo-**THAIR**-uh-pee), sometimes followed by stem cell transplant. Other treatments are used less often.

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

- The type of AML
- The chance that a type of treatment will cure the leukemia or help in some way
- Your age and overall health
- Whether a matched stem cell donor can be found
- Your feelings about the treatment and the side effects that come with it

## **Chemotherapy**

Chemo (KEY-mo) is the short word for chemotherapy – the use of drugs to fight cancer. These drugs go into the blood and spread through the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break.

Treatment of AML is usually divided into 2 parts:

- The first part is called *induction*. Its job is to clear the blood of all leukemia cells. You usually get 2-3 chemo drugs over a week while in the hospital.
- The second part is called *consolidation*. Its job is to kill any leftover leukemia cells and keep the AML from coming back. This treatment is most of the time given over several months. Sometimes it may include a stem cell transplant (see below).

## **Side effects of chemo**

Chemo can have many side effects like:

- Hair loss
- Mouth sores
- Not feeling like eating
- Diarrhea
- Feeling sick to your stomach and throwing up
- Increased 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) 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 restore 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.

## **Surgery**

Surgery 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* or *venous access device* (VAD) into a large vein. This allows drugs such as chemo to be given and blood samples to be taken out.

## **Radiation treatments**

Radiation (pronounced RAY-dee-**A**-shun) 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](#) 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 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 leukemia?
- 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?
- Should we think about a stem cell transplant? If so, when?
- How long do you think I will live?
- What will we do if the treatment doesn't work or if the leukemia comes back?
- What's the next step?

## What will happen after treatment?

Treatment for AML can last for many months. Even after treatment ends, you will need many follow-up exams – likely 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 AML and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You may 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 AML. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

- [Words to know](#)
- [How can I learn more?](#)

**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): 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.

**Bone marrow:** The soft, spongy tissue in the 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.

**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.

**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.

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org). 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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