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EASY READING

If You Have Chronic Myeloid Leukemia (CML)

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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. Some are rare. Most are named based on if they are 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 myeloid leukemia (CML)?

Chronic myeloid leukemia or CML 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 of the time CML grows slowly, but over time the leukemia cells can spill out into the blood and spread to other parts of the body, like the spleen.

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 do we know if I have CML?

How does the doctor know I have CML?

Many people with CML don't have any symptoms. The leukemia is found when blood tests are done for some other health problem or during a routine check-up. Even when there are symptoms, they may be very general and unclear.

Some signs of CML include feeling tired or weak, losing weight, having a fever, or sweating a lot at night. The doctor will ask you questions about your health and do a physical exam.

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

Tests for CML

Blood cell counts: This blood test is often the first test done. Most people with CML have too many white blood cells with many early (not mature) cells, called blasts. Sometimes people with CML have low numbers of other types of blood cells. Even though these results may point to leukemia, most of the time you'll need other blood tests or a test of the bone marrow to make sure.

Bone marrow aspiration and biopsy : For these tests, a doctor uses thin, hollow needles to take out small amounts of bone marrow, usually from the back of your hip bone. The area around 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. These tests may also be done after treatment to see if the treatment is working.

Gene tests: If you might have CML, tests will be done on samples of your blood and/or bone marrow to look for certain gene changes in the cells. CML cells nearly always have certain changes.

Other blood tests: If you have leukemia, other blood tests will be done to see how well your liver, kidneys, and other body parts 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're sometimes done to see if the leukemia has spread to other parts of your body, like the spleen or liver. 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 serious is my CML?

Most types of cancer are assigned a stage based on how much the cancer has spread. This helps the doctor know how to treat the cancer and how likely it is that you'll get better. But CML isn't staged like most cancers. Instead, CML is said to be in one of 3 phases . The phase of CML is based mainly on the number of early white blood cells, called blasts, in your blood or bone marrow. From less serious to more serious, the phases are:

- Chronic phase
- Accelerated phase
- Blast phase (also called acute phase or blast crisis)

Most of the time, CML is in the chronic phase when it's first found.

Questions to ask the doctor

- Does anything about my leukemia cells change the treatment? Or make my case better or worse?
- Are there other doctors I need to see?
- How many people with CML have you treated?
- What phase is my CML in?
- Would you explain to me what my CML phase means for me?
- Based on the phase of my CML, how long do you think I'll live?
- What will happen next?

What kind of treatment will I need?

The kind of treatment you will need depends on the phase of your CML, your age and how healthy you are, and whether a stem cell donor can be found.

The most common kinds of treatment for CML are:

- Targeted drugs
- Interferon
- Chemotherapy
- Stem cell transplant

Targeted drugs

The main treatment for CML is drugs that go after proteins in the leukemia cells that aren't normal. These drugs mainly affect cancer cells and not normal cells. They're pills you take every day. Most of the time, targeted drugs are very good at treating CML. If one targeted drug doesn't work, others may be tried. These drugs can have side effects, but they're often not the same as those of chemo drugs. Ask your doctor which drug you will have and what to expect.

Interferon

Interferons are made by immune system cells in the body. Man-made types of interferon drugs attack the leukemia and slow its growth. They're given as a shot under the skin. Interferon might be tried if targeted drugs don't work or you can't take them. Side effects can include flu-like symptoms, feeling very tired, fever, and weight loss. Ask your doctor what to expect.

Chemo

Chemo (the short word for chemotherapy) is the use of drugs to fight cancer. Most of the time chemo drugs are given into a vein or taken as pills. These drugs go into the blood and spread through the body. In CML, chemo is not usually used unless other treatments are no longer working. Chemo is given in cycles or rounds. Each round of treatment is followed by a rest break. Treatment often lasts for many months.

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
- 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 destroy the bone marrow, which means new blood cells can't be made. Although the drugs destroy the bone marrow, the stem cells given after chemo bring back the blood-making bone marrow stem cells. You may get an SCT if you haven't been helped by other treatments. 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.

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'd 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 clinical trials. See [Clinical Trials¹](#) to learn more.

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 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 might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments might be vitamins, herbs, special diets, and other things. You may be curious 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 these side effects?
- 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'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?
- 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's next?

What will happen after treatment?

If you have CML, you'll be treated with medicines that keep your disease in check. It's important that you take the medicine the way the doctor tells you to. But medicines aren't likely to cure CML, so you'll still need to see your doctor a lot. Be sure to go to all of these visits. Your doctors will ask about symptoms, do physical exams, blood tests,

and maybe other tests to see how well your treatment is working.

Having CML 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 be more healthy. 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 CML. 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/clinical-trials.html
2. <http://www.cancer.org>

Words to know

Biopsy (BY-op-see): Taking out a small piece of tissue or liquid from the body 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 thin, hollow needles are put into the center of a bone, usually the back of 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.

Interferons (IN-ter-**FEAR**-ons): Proteins made by cells that help regulate the body's immune system. Man-made versions of interferon are used to treat some types of cancer.

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

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>)². 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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