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EASY READING

If You Have Chronic Myelomonocytic Leukemia (CMML)

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What is leukemia?

Cancer can start any place in the body. [Leukemia](#)¹ 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 chronic myelomonocytic leukemia (CMML)?

[Chronic myelomonocytic leukemia](#)², or *CMML* for short, is a type of cancer that starts in

cells in the bone marrow that are supposed to grow into different types of blood cells. (These cells are called **monoblasts**.) CMML is slow growing, but over time the leukemia cells can spill out into the blood and reach other parts of the body, such as 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 will the doctor know I have CMML?

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

Some [signs of CMML](#)³ are caused by a large spleen. You may have belly pain or feel full too fast after eating. Other signs include feeling tired or weak, losing weight, fever, lots of infections, and easy bruising or bleeding. The doctor will ask you questions about your health and do a physical and exam.

If signs are pointing to CMML, 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. People with CMML have too many white blood cells called monocytes (mon-o-sites). They may have early (not mature) cells, called monoblasts, in their blood. (Monoblasts should only be in the bone marrow.) They often have low numbers of other types of blood cells. Even though these results may point to leukemia, most of the time you will need more [blood tests](#)⁴ or a test of the bone marrow to make sure.

Bone marrow aspiration and biopsy (ASP-er-AY-shun and BY-op-see): For these tests, a doctor uses thin, hollow needles to take out small amounts of bone marrow, usually 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. These tests may also be done after treatment to see if the treatment is working.

Gene tests: If you might have CMML, tests will be done on samples of your blood or bone marrow to look for certain [gene changes](#)⁵ in the cells.

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

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 CMML?

Most types of cancer are [staged](#)⁶ based on how much the cancer has spread. This can help the doctor know how to treat the cancer and how likely it is that you'll get better. But CMML can't be staged by looking at the size of a tumor. It's split into 2 groups based on cell counts in the blood and bone marrow:

- **CMML-1:** Blasts make up less than 5% of white cells in the blood and less than 10% of the cells in the bone marrow.
- **CMML-2:** Blasts make up 5% to 20% of the white cells in the blood, or they make up 10% to 20% of the cells in the bone marrow.

Questions to ask the doctor

- Are there other doctors I need to see?
- How many people with CMML have you treated?
- What group is my CMML in?
- Would you explain to me what the group means in my case?

- What will happen next?

What kind of treatment will I need?

The kind of treatment you will need depends on your blood counts, your age, your overall health, and whether a [stem cell donor](#)⁷ can be found.

In most cases, treatment is used to prevent or control the problems CMML causes. This may be treatments like [blood transfusions](#)⁸ and drugs called growth factors to help you feel good and have safe [blood cell levels](#)⁹. This is called [supportive care](#)¹⁰.

Stem cell transplant

A [stem cell transplant](#)¹¹ (SCT) is the only way to cure CMML. It 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. SCT is very hard on your body. 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.

Chemo

Chemo is the short word for [chemotherapy](#)¹²— 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 CMML, chemo is may be used to control the number of CMML cells in the bone marrow so healthy cells can grow. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Treatment often lasts for many months.

Side effects of chemo

Chemo can have many side effects, like:

- Hair loss
- Mouth sores
- Not feeling like eating
- Diarrhea
- Sick stomach and throwing up

- More risk of infections
- Black and blue marks and bleeding easily
- Tiredness

These problems tend to get better when treatment ends. There are ways to treat most chemo side effects. Be sure to talk to your cancer care team so they can help.

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 might hear about [other ways](#)¹⁴ 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

- Is transplant an option for me?
- What treatment do you think is best for me?
- What's the goal of this treatment?
- 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 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?
- How long do you think I'll live?
- What will we do if the treatment doesn't work or if the leukemia gets worse?
- What's the next step?

What will happen after treatment?

If you have CMML, you will be treated to help keep your disease in check. But most treatments can't cure the disease, so you will 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 CMML 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](#)¹⁵. 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 CMML. 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/leukemia.html
2. www.cancer.org/cancer/chronic-myelomonocytic-leukemia.html
3. www.cancer.org/cancer/chronic-myelomonocytic-leukemia/detection-diagnosis-staging/signs-symptoms.html
4. www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-lab-test-results.html
5. www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer.html
6. www.cancer.org/treatment/understanding-your-diagnosis/staging.html
7. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/stem-cell-transplant.html
8. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/blood-transfusion-and-donation.html

9. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/low-blood-counts.html
10. www.cancer.org/treatment/treatments-and-side-effects/palliative-care.html
11. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/stem-cell-transplant.html
12. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/chemotherapy.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/treatment/survivorship-during-and-after-treatment/staying-active.html
16. <http://www.cancer.org>

Words to know

Biopsy (BY-op-see): Taking out a small piece of body 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 thin, hollow needles are 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.

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.

Myelomonocytic (MY-uh-lo-mon-uh-sit-ick)

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.

Last Medical Review: October 6, 2017 Last Revised: October 6, 2017

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