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EASY READING

If You Have Waldenstrom Macroglobulinemia

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What is Waldenstrom macroglobulinemia?

Waldenstrom macroglobulinemia (WM) is a type of [non-Hodgkin lymphoma](#)¹ (NHL). The cancer cells make large amounts of an abnormal protein called a macroglobulin. Each protein made by the WM cells is the same, so it is called a monoclonal protein, or just an M protein. The buildup of this M protein in the body can lead to many of the symptoms of WM, including too much bleeding, problems with vision, and nervous system problems.

The WM cells grow mainly in the bone marrow, where they can crowd out the normal cells that make the different types of blood cells. This can lead to low levels of red blood cells ([anemia](#)²), which can make people feel tired and weak. It can also cause low numbers of white blood cells, which makes it hard for the body to fight infection. The numbers of platelets in the blood can also drop, leading to increased bleeding and bruising.

These cancer cells can also grow in organs like the liver and spleen, causing these organs to swell, leading to abdominal pain.

Questions to ask the doctor:

- Why do you think I have cancer?
- Is there a chance I don't have cancer?
- Would you please write down the kind of cancer I have?
- What will happen next?

How does the doctor know I have Waldenstrom Macroglobulinemia?

Waldenstrom macroglobulinemia (WM) is often found when a person goes to see their doctor because of symptoms they are having, or because they just don't feel well and go in for a checkup. Sometimes it's found in people without symptoms when they have blood tests done for some other reason.

Some common symptoms of WM are weakness, loss of appetite, fever, sweats, weight loss, and neuropathy (painful pins-and-needles feeling in the feet/legs). If signs or symptoms suggest that a person might have WM, exams and tests will be done to be sure. The most important tests will look for abnormal proteins in the blood and abnormal cells in the bone marrow.

The doctor will ask you questions about your health and do a physical exam.

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

Blood cell counts: This blood test is often the first test done. People with WM may have a low red blood cell count.

Blood tests for immunoglobulins: Samples of your blood might be tested for immunoglobulins (another name for antibodies). Levels of one of these proteins (IgM) are typically higher than normal in people with WM.

Viscosity: Viscosity is a measure of how thick the blood is. If the IgM protein level is too high, the blood will become thick (viscous) and can't flow freely (think about pouring honey compared to pouring water).

Bone marrow aspiration and biopsy: For these tests, 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 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 WM cells in the bone marrow.

Other biopsy tests: If you have a tumor or an enlarged lymph node, a thin, hollow needle attached to a syringe might be used to remove a small piece of it. The sample is then tested for cancer cells.

CT scan: This is also called a CAT scan. It's a special kind of x-ray that takes detailed pictures of the body. CT scans can help show if there are any enlarged organs from the cancer.

MRI scan: MRIs use radio waves and strong magnets instead of x-rays to take detailed pictures. MRI scans can be very helpful in looking at the bones and bone marrow.

PET scan: This test uses a special kind of sugar that can be seen inside your body with a special camera. This sugar shows up as hot spots where the cancer is.

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?

How serious is my Waldenstrom Macroglobulinemia?

If you have cancer, the doctor will want to find out how advanced it is. This is called staging.

For WM, there is no standard staging system because this hasn't been shown to be important when looking at outcomes or deciding on treatment.

Instead, doctors look at other factors, such as age, blood cell counts, the amount of immunoglobulin (IgM) in the blood, and the level of another protein in the blood called beta-2 microglobulin (2M). People with lower levels of IgM and 2M tend to do better than those with higher levels. People with WM who are older, are anemic (based on a

low blood hemoglobin level), or have a low blood platelet count tend to have a poorer outlook. Experts have used these factors to help predict the outlook for patients with WM.

Be sure to ask the doctor about the specific factors of your cancer and what it means for you.

Questions to ask the doctor:

- Do you know how advanced my cancer is?
- Based on the specifics of the cancer, how long do you think I'll live?
- What will happen next?

What kind of treatment will I need?

The treatment plan that is best for you depends on your age, overall health, and other factors, such as symptoms you are having. If the WM is found early and is not causing symptoms, you might not need to be treated right away. You might just be watched closely instead. If you do need treatment, it could include:

- Chemotherapy
- Targeted therapy
- Immunotherapy
- Stem cell transplant
- Radiation
- Plasmapheresis

Chemo

Chemo is the short word for chemotherapy – the use of drugs to fight cancer. The drugs are often given into a vein. These drugs go into the blood and reach almost all areas of the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Most of the time, 2 or more chemo drugs are given. 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
- Feeling sick to your stomach and throwing up
- More risk of infections
- Bruising 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.

Other drug treatments

Many other types of drugs can be used to treat WM or its symptoms. These drugs work differently from chemo. Some of them target parts of WM cells that make them different from normal cells. Others help your immune system attack the WM cells. Often, different types of drugs are combined (sometimes along with chemo). Plasma exchange may be done to remove the abnormal protein to make the blood less thick to lower the risk of bleeding problems or stroke.

Some of these drugs are taken as pills, while others are injected into a vein. Each of these drugs can have its own side effects, so ask your doctor about which drugs you will get and what to expect.

Stem cell transplant

A stem cell transplant (SCT) lets doctors use very high doses of chemo to kill the WM. 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 normal blood-making bone marrow stem cells. There are different kinds of SCT, each of which can have 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 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 Trials³](#) 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 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? How is it likely to help?
- Will I need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Should we think about a stem cell transplant? If so, when?
- 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 often will not cure WM, but it might make it go away for a time. If you have WM, there might be times when you are not being treated. Or you might continue to get regular treatments with chemotherapy and other drugs, or other treatments to try to help keep the cancer in check.

Whether or not you are being treated, ongoing follow-up is very important. Your doctors will ask about symptoms, do an exam, and might order blood tests or tests like CT scans or x-rays. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

Having cancer 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 cancer. 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/non-hodgkin-lymphoma.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/low-blood-counts/anemia.html
3. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
4. <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): 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.

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>)⁴. 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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