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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

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?

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. To replace the destroyed bone marrow, doctors use stem cells that have been collected from the patient before treatment or from a donor.

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

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

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.org⁴. 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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The American Cancer Society medical and editorial content team
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Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as editors and translators with extensive experience in medical writing.

