



Waldenstrom's macroglobulinemia (WM)

Patient Guide

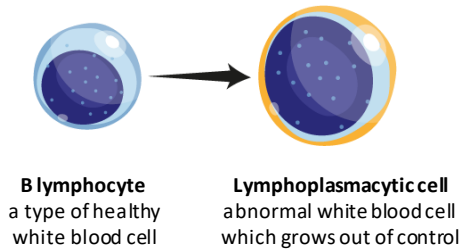


What is WM?

Waldenstrom's macroglobulinemia is a rare type of blood cancer with an estimated 1,500–3,000 cases per year in Europe and the U.S.

In WM, healthy blood cells transform into abnormal (cancerous) white blood cells that build-up in the bone marrow. These abnormal cells can also grow in other areas such as the lymph nodes, spleen, lungs, brain, and spine.

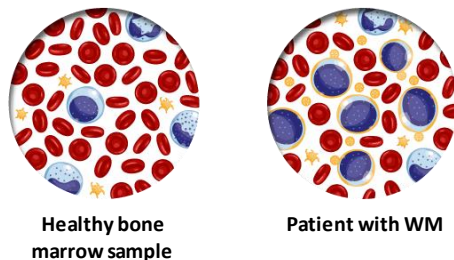
You may also hear WM referred to as "lymphoplasmacytic lymphoma".



Excess amounts of a large protein called 'IgM' are made by these abnormal cells.



The cancer cells crowd out healthy cells that the body needs to function properly, while excess IgM thickens the blood.



What are the symptoms?

Some people with WM experience symptoms caused by abnormal cancer cells and/or IgM proteins, while others can be asymptomatic for a long time.

Symptoms include:

Fatigue, tingling, numbness, and weakness

Bleeding in the eye or brain, caused by an excess of IgM that thickens the blood

Enlarged spleen or lymph nodes, caused by the build-up of abnormal white blood cells

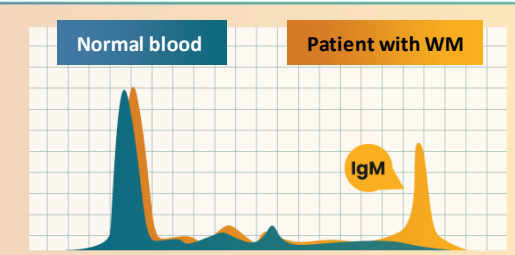
Anemia, caused by abnormal white blood cells crowding out healthy red blood cells

There are other, rarer symptoms caused by excess IgM protein, which can affect a number of organs and tissues including blood vessels and nerves, and may also cause other forms of anemia.

How is WM diagnosed?

Blood tests:
to check the number of blood cells and IgM protein levels

A bone marrow biopsy:
to check for abnormal cells



What will my treatment plan look like?

Treatment usually starts when symptoms begin, often if you have low healthy blood cell counts or a high tumor load, causing fatigue and bleeding; or if you have very high levels of abnormal IgM protein, causing symptoms relating to a thickening of the blood or damage to cells and organs.

If no symptoms are present, you may not need treatment, but you will be monitored through regular blood tests.

There is currently no cure for WM, but many treatments are now available; you will have time to talk through the best options with your doctor.

Talk to your doctor if you experience any side effects from your treatment and they can advise you on how to manage them. You may also want to speak with another doctor to get a second opinion on your diagnosis and treatment.



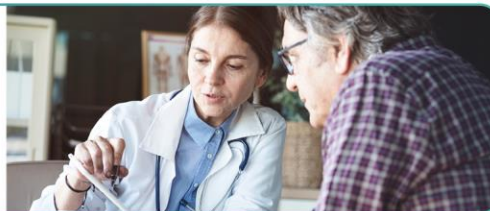
Treatment usually consists of a pill taken on an ongoing basis, or a drip infusion given for a fixed time.



Rituximab is a commonly used treatment; however, this comes with a short-term risk of an increase in IgM (called an IgM flare). This may need to be managed using plasmapheresis, a temporary measure to reduce IgM in patients with WM. A machine connected to a vein replaces plasma with donated plasma.

What happens after treatment?

There is a chance that the disease may come back at any point after treatment; however, there are treatment options available at this stage.



What is the life span of patients with WM?

Life expectancy has improved in recent years. Some WM experts give an estimated life span of 15–20 years from diagnosis, but this will continue to increase as safer and more effective drugs become available.



Where can I get help?



The International Waldenstrom's
Macroglobulinemia Foundation

website: www.iwmf.com

phone: 001-941-927-4963



Scan with your phone camera
to visit www.iwmf.com

On the IWMF website, you can:

- Download a free [Newly Diagnosed 'Info Pak'](#)
- Download free publications about WM written in a clear, easy-to-understand style and available in multiple languages
- Join a local IWMF Support Group or global affiliate
- Join IWMF Connect, an online community offering a wide variety of moderated WM-related email discussions, or IWMF Facebook
- Attend the annual IWMF Educational Forum or our online webinars
- Subscribe to the IWMF Torch, our free quarterly newsletter
- Contact an IWMF affiliate: iwmf.com/international-affiliates
- Contact an IWMF partner: iwmf.com/partners
- Work with your medical team to contact the IWMF Directory of Physicians for a second opinion: iwmf.com/directory-of-wm-physicians

[For further information, read the IWMF 'Essential Information: A Patient's Guide on Waldenstrom's Macroglobulinemia' resource](#)



The International Waldenstrom's Macroglobulinemia Foundation (IWMF) and the Lymphoma Hub are working in collaboration for patients with Waldenstrom's macroglobulinemia. This initiative aims to increase awareness of Waldenstrom's macroglobulinemia among healthcare professionals, patients, caregivers, and the patient advocacy community. This initiative is funded by Collectar Biosciences. All content is developed independently by SES in collaboration with an expert steering committee; funders are allowed no direct influence on the content of the hub.