Waldenstrom's macroglobulinemia (WM)

Patient Guide

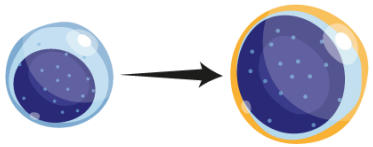
17 APRIL
Waldenström's macroglobulinemia
World Awareness Day

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".

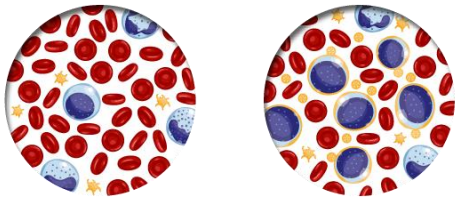


B lymphocyte
a type of healthy white blood cell

Lymphoplasmacytic cell
abnormal white blood cell which grows out of control

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.



Healthy bone marrow sample

Patient with WM

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:

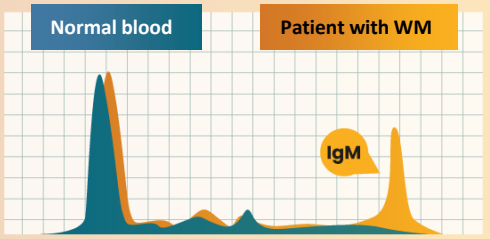
Fatigue, tingling, numbness, and weakness	Bleeding in the eye or brain, caused by an excess of IgM that thickens the blood
Enlarged spleen or lymph nodes, caused by the build-up of abnormal white blood cells	Anemia, caused by abnormal white blood cells crowding out healthy red blood cells

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?

In Aotearoa New Zealand's Affiliate is called Waldos. You can find information about the local scene at:

www.waldos.kiwi

Our growing group of 52 members, some of whom are available throughout our country, and happy to be contacted if you'd like to talk.

You are Not Alone

We hold occasional virtual meetings

You will receive information gathered from international WM experts and relevant to New Zealand Waldenström patients.

IWMF

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**

IWMF | CELLECTAR BIOSCIENCES

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 Cellectar 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.