# Waldenström macroglobulinaemia

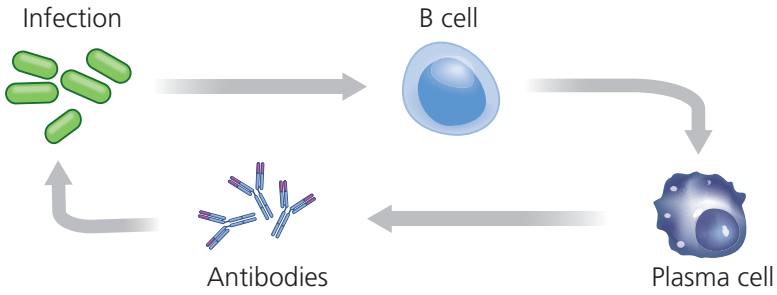
**You or a family member have been diagnosed with Waldenström macroglobulinemia (WM). This leaflet gives you some basic information about the condition and helps answer some of your questions.**

## What is WM?

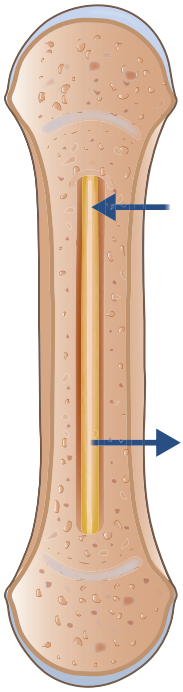
WM is a rare and slow-growing blood cancer. It happens when a type of blood cell in your body develops in an unusual way. WM is not inherited but close relatives (father, mother, brother, sister or child) of a person with WM have a higher risk of also having WM. This is called a 'genetic predisposition'. The blood cells involved in WM are a type of white blood cell called a **B cell**. In a healthy person, B cells change into **plasma cells**. The plasma cells can then make antibodies to fight infection.

## Is there a cure for WM?

There is currently no cure for WM but there is treatment that many people can have to keep the disease under control. The quality of life and survival for WM patients are continuing to improve because of better treatments.




## More about normal blood cell production



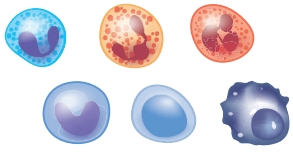
**Bone marrow** is the spongy material found inside larger bones such as your breast bone, spine, ribs, skull, hips and the long bones of your arms and legs. Blood cells are made in the bone marrow.

**Three types of blood cell** develop in your bone marrow

**Red blood cells** carry oxygen around your body

**Platelets** help your blood to clot

**White blood cells** fight infection. There are several different types which are important for immunity



If you have WM, some of your B cells cannot make plasma cells and instead they make cells called **lymphoplasmacytic (LPL) cells**. This is why WM is sometimes called '**lymphoplasmacytic lymphoma**'.

## Why are LPL cells a problem?

Too many LPL cells in the bone marrow can reduce the production of normal red blood cells. This can lead to anemia. Anemia can cause extreme tiredness, weakness, and breathlessness.

When LPL cells build up in the body, they can clump together, usually in the bone marrow, lymph nodes and spleen. This can cause swelling.

LPL cells make large amounts of a protein called immunoglobulin M (IgM). Another name for these is IgM paraproteins or M proteins. They are found in the blood-stream of nearly all people with WM.

## How will WM affect me?

Symptoms vary from person to person depending on how the disease develops. Even after diagnosis, you may not get any symptoms for many years and not need any treatment.

**Symptoms may develop because of:**

- disrupted production of normal blood cells
- thickening of the blood because of the high levels of IgM paraprotein
- IgM paraproteins targeting tissues and organs
- the IgM coating nerve cells and causing damage (peripheral neuropathy).

Over time, LPL cells fill up the bone marrow or collect in the lymph nodes or the spleen (and, rarely, in other places in the body).

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# Waldenström macroglobulinaemia ... *contd*

## What tests will I need?

### Blood tests

Blood samples will be taken for different tests. These include:

- **Complete or full blood count:** measures different types of cells in your blood.
- **Metabolic panel:** measures different chemicals to assess the health of your kidneys, liver and bones.
- **Immunoglobulin tests:** detect excessive production of immunoglobulin and identify IgM paraprotein in your blood
- **Serum or plasma viscosity:** measures the thickness of your blood

## What is the treatment for WM?

What treatment you need – or whether you need any at all – depends on how far WM has developed and other factors, like your health or age.

**Active Monitoring:** this is sometimes called 'Watch and Wait'. You will have check-ups and blood tests every 3–6 months and your doctor will look for any signs that WM is developing.

**Plasma exchange:** when there is too much IgM in your blood and it is too thick, a machine called a cell separator thins the blood by removing the IgM. The process typically takes 3 or 4 hours.

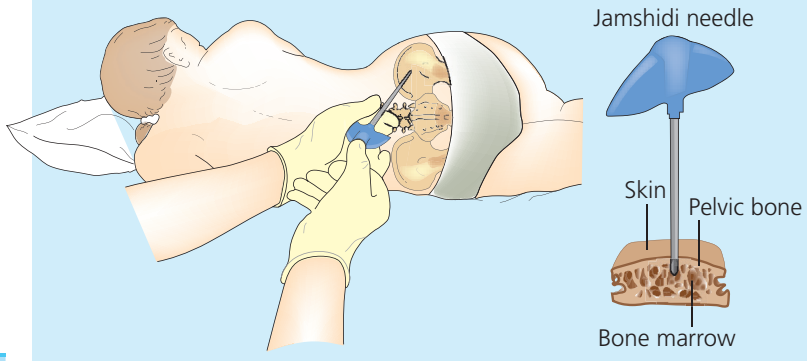
**Chemotherapy:** chemotherapy kills cancer cells or stops them from growing.

**Targeted therapies:** these are newer drugs that can be used on their own or in combination with chemotherapy.

**Stem cell transplant:** is sometimes used to treat WM but it is not suitable for every patient.

## Bone marrow biopsy

A bone marrow biopsy takes a sample of the bone marrow to confirm that LPL cells are present, how many there are and how much normally functioning bone marrow remains. The doctor will usually take the sample from the back of your hip bone (pelvis).




The procedure can be uncomfortable but you will have a local anaesthetic to numb the area. It is quick and takes around 20 minutes. The biopsy is usually done at a hospital.

## What now?

If you're on Active Monitoring you will probably see a **hematologist-oncologist** (a doctor who specializes in blood cancers) every few months. The hospital will also assign a key worker, usually a **clinical nurse specialist**.

If you're having treatment, you'll probably be cared for by a specialist team of healthcare professionals. As well as a hematologist-oncologist and a specialist nurse, who you see will depend on your symptoms.

You may see
- **an ophthalmologist** (eyes)
- **a neurologist** (nerves)
- **a cardiologist** (heart)

Where you go for your appointments depends on where you live. You may go to a clinic specializing in WM or to the hematology department in your local hospital.

## More help and information

WM UK
wmuk.org.uk
facebook.com/WMUKsupport/

Blood Cancer UK
bloodcancer.org.uk

Lymphoma Action UK
lymphoma-action.org.uk

Alliance for Cryoglobulinemia
allianceforcryo.org

Amyloidosis Foundation
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