

# Waldenström's macroglobulinemia FAQs

## Frequently asked questions from patients

### Am I at risk of developing WM?

The exact cause of WM is unknown; however, WM is more common in people older than 65. It also occurs slightly more often in men than in women.<sup>1</sup>

If you have a family member with lymphoma, you have a higher risk of developing WM. But WM is very rare; there is a very low risk of your family members getting it.<sup>1</sup>

Like other cancers, WM is not infectious, so you do not have to worry about passing it on to family and friends.<sup>1</sup>

### How many tests will I need?

The most common tests used to diagnose WM are blood tests and bone marrow tests.<sup>1,2</sup>

You may also have a scan to look at specific organs, such as your liver or spleen. These scans will also assess the lymph nodes in your body.<sup>1,2</sup>

Waiting for your test results can be challenging. So, make sure to reach out to your family, friends or specialist nurse if you have any concerns.<sup>1</sup>

### How invasive is a bone marrow test?

A doctor or nurse will take a small sample of bone marrow from your pelvis or sternum. This sample is then sent to be checked for any abnormal cells.<sup>3</sup>

A bone marrow test can be done in a hospital or clinic. It usually takes up to 30 minutes, but removing the bone marrow sample will only take a couple minutes.<sup>3</sup>

You will always be given a local anaesthetic to numb the area before any bone marrow sample is taken. If need be, you may also receive a sedative to reduce any pain during the procedure.<sup>3</sup>

During the procedure, a doctor or nurse will pass a needle through your skin into the bone. This allows them to take a small sample of liquid from inside the bone marrow into a syringe. This can feel uncomfortable but will only last for a few seconds.<sup>3</sup>

### How long do I have to wait for my results?

You may have to wait a few days or a few weeks for your test results. You may feel anxious during this time. However, it is better to wait until a diagnosis is made before looking for more information.

If you need support, make sure you reach out to your partner, family, close friend, or specialist nurse.<sup>1</sup>

### Will I be referred to a specialist?

Following your diagnosis, a team of specialists will meet to decide the best possible treatment for you specifically. This team is known as your multidisciplinary team.<sup>1</sup>

Your doctor, cancer specialist or nurse will explain which treatments are available to you and what side effects they may cause. They will also talk to you about things to consider when making your treatment choice.<sup>1,4</sup>

### Why am I not being offered treatment straight away?

WM often develops slowly. Some people may not need treatment straight away, or even for months or years. This is called watch and wait.<sup>1</sup>

Even if you do not need treatment, your specialist will examine you and do blood tests. This is to check the levels of IgM protein in your blood and the number of red blood cells, white blood cells and platelets.<sup>1</sup>

These regular appointments are known as 'active monitoring', 'watch and wait' or sometimes 'active surveillance'. You will continue to receive them until you need treatment.

### What symptoms should I look out for?

WM usually develops over a long period. During this period, you may not have any symptoms.<sup>1</sup>

However, it is the build-up of lymphoma cells in your bone marrow that can cause symptoms. This is because the lymphoma cells take up space, making it difficult for the bone marrow to produce enough blood cells.<sup>1</sup>

The most common symptoms you may experience are<sup>1</sup>:

- Weight loss
- Looking very pale or feeling breathless because of a lack of red blood cells (anaemia)
- Repeated infections because of a lack of healthy white blood cells (which help fight infection)
- Feeling weak and tired (fatigue)
- Bruising or bleeding easily
- Heavy, drenching night sweats

### What types of treatment are there?

During your regular check-ups, your doctor will be able to identify exactly when you need to start treatment. Treatment will typically begin if<sup>1</sup>:

- Your blood count changes
- You have troublesome symptoms
- The level of IgM protein in your blood has increased

The aim of treatment is to improve your quality of life for as long as possible, with the fewest possible side effects.

- The main treatments for WM are<sup>1</sup>:
- Targeted therapies
- Stem cell transplants
- Chemotherapies
- Steroids

You may also need a blood transfusion if you have symptoms caused by a low number of red blood cells<sup>1</sup>.

### What are the potential side effects of treatment?<sup>5</sup>

Some people have side effects during their treatment and for a few weeks after. However, these side effects will eventually disappear.

In some cases, side effects continue for months after treatment. Other people may have side effects that develop years after treatment.

Not everyone has long-term or late effects. Most people will find that their side effects get better over time. However, this is dependent on the treatment you receive.

These are some of the side effects you may experience:

- Tiredness
- Peripheral neuropathy
- Infections
- Thyroid changes
- Early menopause or menopausal symptoms in women

## References

- [1] Macmillan. Waldenström's macroglobulinemia. Updated 21 January 2018. Accessed April 2021. <https://www.macmillan.org.uk/cancer-information-and-support/lymphoma/waldenstroms-macroglobulinaemia>
- [2] Gertz MA. Waldenström macroglobulinemia: 2019 update on diagnosis, risk stratification, and management. *Am J Hematol.* 2019;94(2):266–276.
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- [4] Bomhof-Roordink H, *et al.* Shared decision making in oncology: a model based on patients', health care professionals', and researchers' views. *Psychooncology.* 2019;28(1):139–146.
- [5] Macmillan. Late effects of treatment for lymphoma. Updated 31 January 2018. Accessed April 2021. <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/late-effects-of-treatment-for-lymphoma>

WM=Waldenström's macroglobulinemia.

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