Waldenstrom's macroglobulinaemia: Related conditions and symptoms

A guide for people living with WM

0300 373 8500 | support@wmuk.org.uk | wmuk.org.uk

We're here for **you.**

This guide was made possible by the generous support of the WM community and its supporters.

If you have any questions about any aspect of WM – including symptoms, treatments and help available – visit our website wmuk.org.uk contact our Support Line on **0300 373 8500** or email us at support@wmuk.org.uk

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About this guide

This guide has been created specifically for those living with Waldenstrom's macroglobulinaemia (WM) and their friends and family.

We want to help you find out more about the symptoms and conditions associated with WM, together with the treatments and help available to you, so you can live well.

Everyone's experience of WM is different. Some people may have a range of symptoms, while others may only have a few. Sometimes these are caused by WM itself and sometimes by other conditions related to the disease.

In this guide, we have listed potential symptoms, the conditions that may be causing them and possible treatments. Use this guide for reference, but remember, if you are concerned about any symptoms, please contact your healthcare team.

If you need more in-depth information about WM or want further details about the support available to you, your family and friends just go to our **Other Resources** section on page 43 of this guide, where you'll find useful links and contact numbers – including our free WMUK Support Line: 0300 373 8500.

- All the information in this guide is intended for people living and being treated in the UK, so some information may not be accurate for those living abroad.

This guide has been created for you in consultation with expert healthcare professionals and people living with WM. However, it can only give general guidance and should not replace the personalised advice and care given to you by your healthcare team.

Find advice and support for friends, family and carers on our website: Friends, family & carers – WMUK

What is WM?

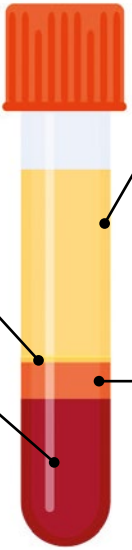
Waldenstrom's macroglobulinaemia (WM) is rare type of blood cancer.

- It is a form of blood cancer called lymphoma, belonging to a group of cancers known as 'Non-Hodgkin Lymphomas'
- WM isn't curable at the moment, but there are many effective treatments
- Because WM is slow-growing, it doesn't always need treating right away
- You may hear it referred to as lymphoplasmacytic lymphoma (LPL), as it is a type of LPL
- There are around 4,000 people living with WM in the UK
- Symptoms can vary from person to person

What causes WM?

WM is a cancer of the blood.

Your blood is made up of different parts: red blood cells, white blood cells and platelets. These cells are made inside your bones, in what's known as your bone marrow.



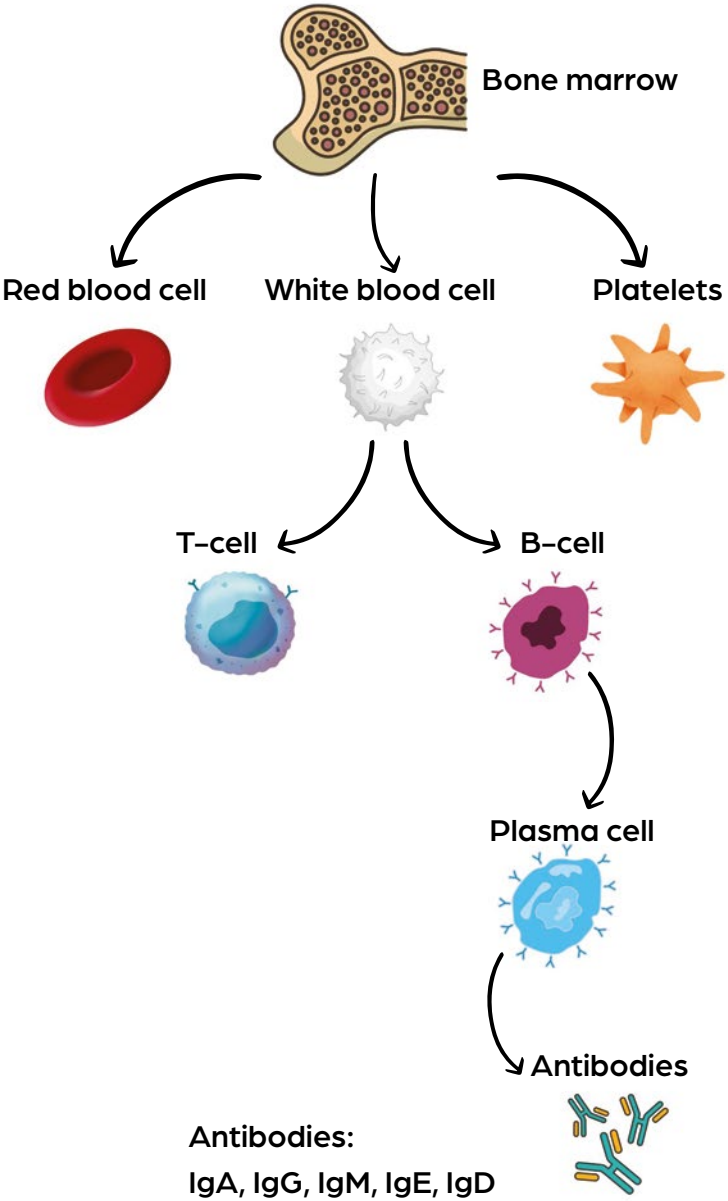
Plasma
The liquid part of the blood that carries white blood cells, red blood cells and platelets around your body

White blood cells
Help fight infection

Red blood cells
Carry oxygen around the body

Platelets
A type of cell that helps blood to clot and prevent bleeding

Normal blood cell production



With Waldenstrom's macroglobulinaemia, it is a type of white blood cell called B-cells, or B lymphocytes, that develop abnormally. Even though these abnormal B-cells aren't of any use to your body, they keep getting produced and crowd out the other, healthy, cells.

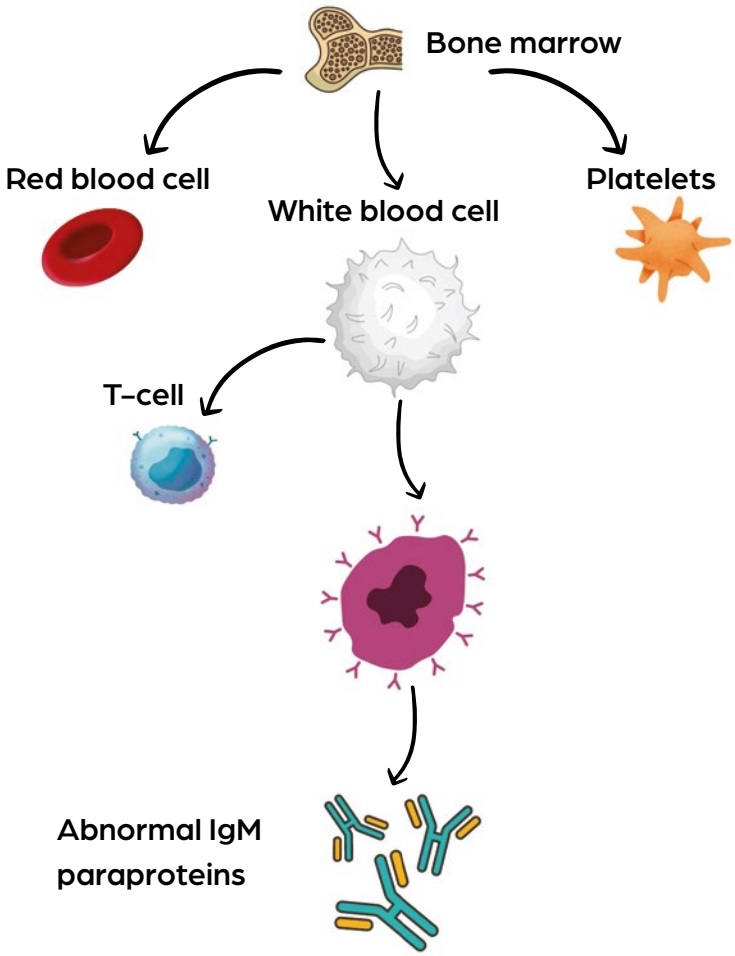
This means the healthy cells can't do their jobs properly, causing many of the symptoms people with WM feel.

For example, the abnormal cells might take up the space of healthy red blood cells. Red blood cells carry oxygen around your body. When you don't have enough of these cells, you develop anaemia which can make you feel overly tired and short of breath.

When your platelets are affected by the abnormal WM cells, you might find you start bruising easily, or even start bleeding from your nose or gums. When you injure yourself, platelets bind together to stop the bleeding. If you have low levels of platelets – called thrombocytopenia – your body can't react as well as it could do, leading to bruising or bleeding.

Some types of healthy white blood cell help your body fight infections by producing antibodies. When you have WM, your body doesn't produce enough of the healthy cells, and therefore there aren't enough antibodies. This means your immune system is lowered and you are at an increased risk of getting serious infections.

Blood cell production in WM



Instead of developing normal B-cells, something goes wrong and some white blood cells develop into lymphoplasmacytic lymphoma (LPL) cells. The abnormal cells can also produce antibodies (or 'paraproteins'). In people with WM, these are the IgM antibodies, and the higher levels of them in your body can cause a range of symptoms.

You can read more about these symptoms in the next section.

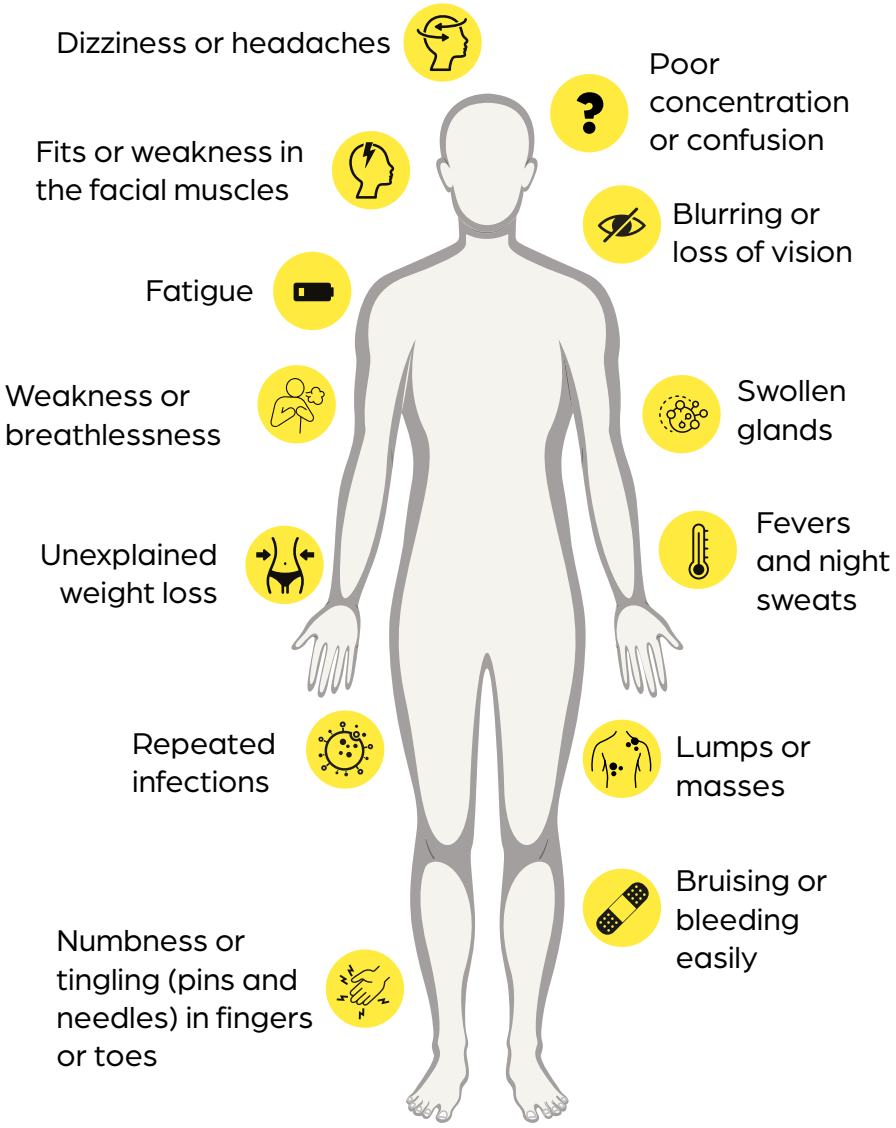
You can find further information about WM in our booklet:

Diagnosed with Waldenstrom's Macroglobulinaemia?

A guide to help you understand your diagnosis and get the support you need.

Common symptoms associated with WM

Often, people don't realise they have WM because symptoms can take many years to develop. Some people have a lot of symptoms, whilst others only have a few. The most common symptoms to look out for are:



These are symptoms of WM. However, they can also be symptoms of a condition caused by WM, or something unrelated to WM. That's why it's important that you let your healthcare team know about any symptoms you experience so they can carry out the correct tests.

You may receive a treatment or medicines to take care of your symptoms, or you may get a treatment that tackles the cause of the symptom. Sometimes you will have both.

It is very important to speak to your healthcare team if you experience any symptoms – even ones not listed in this guide – so they can give you expert advice and arrange for the right tests to be done.

Types of WM treatment

WM responds well to treatment. What type of treatment you have, and when you have it, will depend on your individual circumstances. It might be years until you need treatment, or you may need it straight away.

There isn't a cure for WM. Instead, the aim of WM treatment is to send the disease into what is known as 'remission'. This is when the cells that cause your WM have been reduced, leading to a reduction or improvement in your WM symptoms. This might help you to feel better than before you went on treatment.

Your first course of treatment is called a 'first-line' treatment. The usual first-line treatment is chemotherapy, but your healthcare team will talk through the options that best suit you.

Over time, the abnormal cells in your body may start to increase again, and you might need a second, or even third, course of treatment. These courses are known as 'second-line' and 'third-line'. These treatments might be chemotherapy, but there are also other options that may be available to you, like BTK inhibitors and stem cell transplants.

Chemotherapy

Chemotherapy is a type of drug, or combination of drugs, that kills cancer cells. When treating WM, it is often combined with a type of drug known as a monoclonal antibody, such as rituximab. The most common combinations of chemotherapy that have proven to be effective in treating WM are known as DRC (which contains the drugs dexamethasone, rituximab and cyclophosphamide) and BR (bendamustine and rituximab).

You'll be regularly monitored when you're having chemotherapy, as it can have harsh side effects, including making you more vulnerable to infections. Your healthcare team will advise you of the side effects, and what to do if you get any symptoms. You'll usually receive chemotherapy as an outpatient at your hospital, meaning that you won't need to stay overnight.

Chemotherapy is given in cycles. You'll receive drugs at certain points in a cycle (usually the start), before having a period of rest to let your body recover. The length and number of the cycles depends on how the disease responds and any side effects you may experience. The standard is to give six cycles of chemotherapy, but sometimes this is shortened or doses reduced.

You can find more information about chemotherapy on our website:

www.wmuk.org.uk/your-journey-with-wm/glossary/chemotherapy

BTK inhibitors

BTK inhibitors are a fairly new type of drug that target cancer cells to kill them or stop them from growing. They target a certain part of the WM cells and block them, killing the cells. In England and Wales, the BTK inhibitor zanubrutinib is available to some WM patients as a second-line treatment. In Scotland, zanubrutinib and another drug ibrutinib are available to WM patients.

You can find more information about BTK inhibitors on our website:

www.wmuk.org.uk/your-journey-with-wm/wm-treatment/targeted-treatments-wmuk

Stem cell transplants

This is a procedure that replaces damaged cells in your body with healthy cells. It is an intensive treatment that is only offered as a second- or third-line treatment. A stem cell transplant requires a long stay in hospital of at least a few weeks, and carries a risk of severe side effects. Recovery time can be a year. This means that it is only suitable for a very few WM patients.

You can find more information about stem cell transplants on our website:

www.wmuk.org.uk/your-journey-with-wm/wm-treatment/stem-cell-transplants-for-wm

Conditions related to WM

WM can cause a number of other conditions to develop, some of which are more common, and some which are very rare. The symptoms vary for each condition and will also be different for every individual. In the next few pages, we'll explore some of these conditions and the symptoms you need to be aware of. Remember, it's important to contact your healthcare team if you are concerned about any symptoms whether you think they are associated with one of these conditions or not.

These conditions include:

- Hyperviscosity Syndrome (HVS)
- Cold agglutinin disease (CAD)
- Peripheral Neuropathy (PN)
- Cryoglobulinaemia
- AL amyloidosis
- Bing-Neel Syndrome (BNS)

Hyperviscosity Syndrome (HVS)

Symptoms

- Headaches
- Confusion
- Nosebleeds
- Blurred vision

About HVS

Hyperviscosity syndrome (HVS) affects between 10 and 30% of people who have WM.

If your WM cells make too much IgM antibody, it can make your blood thicker and stickier than normal. **HVS can be dangerous so it's important to contact your healthcare team right away if you experience any of the symptoms.**

Diagnosis

If you have symptoms of HVS you may have a blood test called a plasma viscosity test. This measures the thickness of the blood. This is more accurate than measuring the levels of IgM in the blood because not everyone with high IgM levels will have HVS.

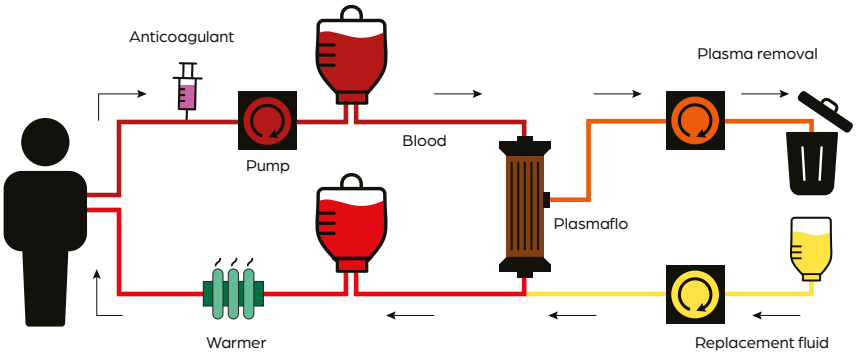
Treatments

Having HVS can be a sign that your WM needs treatment. The treatment helps to lower the level of WM cells so that you don't produce too much IgM. This will limit the number of abnormal antibodies in your blood.

There are several treatment options, which your healthcare team will discuss with you. More information about these treatments can be found in the **Types of WM Treatment** section of this guide (page 14).

HVS can cause a blockage of major blood vessels which could reduce the blood flow to your vital organs, like your brain or heart. It is therefore important to reduce the amount of IgM that is already in your blood. This should be done as soon as possible.

If you are diagnosed with HVS you may also be offered plasma exchange or plasmapheresis. The aim of this treatment is to make your blood less thick. This is done by exchanging the blood plasma (the part of the blood where the large IgM antibodies are) with a replacement fluid similar to plasma.



Plasma exchange works by taking blood out of your body through a needle put into a vein (similar to donating blood) and passing it through a machine.

The machine separates the thick plasma from the rest of your blood and swaps if for a thinner liquid fluid, before it is sent back to your body. This keeps most of the good and healthy parts of the blood, but the harmful sticky plasma is removed. Most people need between one to three plasma exchange sessions to reduce the IgM levels and stickiness. Each session lasts about 90 minutes.

It is very important to speak to your healthcare team if you experience any symptoms – even ones not listed in this guide – so they can give you expert advice and arrange for the right tests to be done.

Cold agglutinin disease (CAD)

Symptoms

- Fatigue
- Shortness of breath
- Painful fingers and toes when it's cold
- Dizziness
- Dark urine
- Pale/yellow skin (jaundice)
- Chest pains or irregular heartbeat

About CAD

CAD is a rare condition where abnormal IgM antibodies make red blood cells stick together. This is called agglutination and it usually happens when your body gets cold. The 'clumps' of red blood cells get stuck in the coolest parts of your body, like your hands and feet, tip of your nose or ear lobes. This can cause the red blood cells to break open.

Red blood cells carry oxygen around the body and are therefore very important. So, if lots of red blood cells break open, oxygen can't get around your body very well. This will make you feel very tired, and sometimes breathless.

The condition isn't always linked to the level of IgM in your blood. So some people who only have a little abnormal IgM may get CAD.

CAD shares some similar symptoms to Cryoglobulinaemia which is described on page 29 of this guide, and some people have both these conditions together.

Diagnosis

If you have symptoms of CAD you'll have blood tests to help diagnose it. Unlike regular blood tests, your blood sample is kept warm until it gets to the laboratory, so it's important that your healthcare team are aware you are being tested for CAD.

Treatments

The easiest way to prevent CAD is to keep warm. You could do this by:

- Wearing more clothes, both in summer and winter, especially in windy conditions
- Wearing thermal gloves and socks to keep your hands and feet warm
- Avoiding air conditioning where possible
- Avoiding cold food or drink

If there are signs that your CAD is getting worse, treatment may be started to lower the level of WM cells. You may have blood transfusions and treatment such as rituximab, which is a type of immunotherapy drug. You can find out more about rituximab in the **Types of WM Treatment** section of this guide (page 14).

Newer drugs are being developed called 'complement inhibitors' that prevent the breakdown of red blood cells. This treatment is currently only available to people who join a clinical trial to test the drugs. Speak with your healthcare team if you are interested in joining a trial or take a look at the WMUK website where you'll find information on current trials.

www.wmuk.org.uk/wm-clinical-trials-hub

Useful to know

If you have CAD and ever need to have a blood transfusion or intravenous infusion, your treatment provider will need to warm the fluid up before giving it to you. Therefore, it's important that anyone treating you is aware of your diagnosis.

Peripheral Neuropathy (PN)

Symptoms

- Feeling unsteady
- Tingling or 'pins and needles' in the feet or hands
- Numbness in the feet or hands
- Problems with walking or co-ordination
- Tremors
- Muscle weakness
- Burning pain, stabbing pain, or shooting pain in feet or hands

About PN

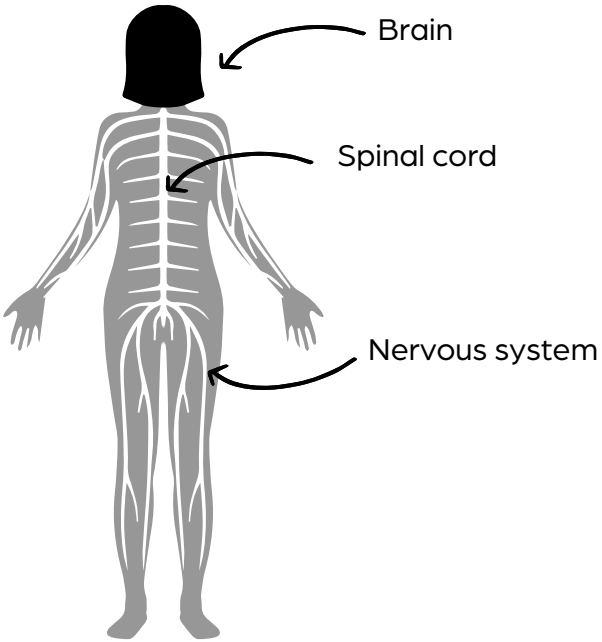
It is fairly common for people with WM to be affected by damage to the nerves in the arms and legs – the peripheral nervous system. This damage is known as peripheral neuropathy (PN) and just under half of WM patients (about 47%) are affected by PN.

The peripheral nervous system carries the messages between the spinal cord and the body so that we can feel and move, behaving much like a system of electrical wires.

There are different types of nerves:

- The sensory nerves carry information up to the brain and spinal cord and let us know what things feel like, give us information about temperature and pain but also where our hands and feet are. They are important for balance and coordination.
- The motor nerves bring impulses downwards to the muscles and tell muscles to move.
- The autonomic nerves work automatically and do things like control our bowel and bladder, our blood pressure and heart rate, and our sweat and temperature control.

When the peripheral nerves get damaged, it causes either too many or not enough messages to be sent around the body, causing a range of symptoms.



A few different types of PN can occur in someone with WM, sometimes as a complication of the WM itself and occasionally as a side effect of one of the treatments. One possible type of PN, is anti-MAG neuropathy. MAG stands for myelin-associated glycoprotein. It is part of the coating that covers the nerve endings, a bit like insulation on an electrical wire. Abnormal IgM can attach to MAG and damage the nerves causing some unsteadiness with walking and abnormal feeling in the feet. This is usually a very slowly changing type of PN and does not always impact how your WM is treated.

Peripheral neuropathy (PN) can be caused by many different diseases, including WM. It's important to watch out for symptoms and report them to your healthcare team as soon as possible to prevent any nerve damage getting worse.

Diagnosis

If you have symptoms of PN, you may be referred to a specialist nerve doctor called a neurologist. They will ask questions and run tests to find out if you have PN, what has caused it and what type of PN it is – for example if it's anti-MAG PN or another type of nerve damage related to WM.

They will ask you about your symptoms, how fast the symptoms developed and/or changed, and any treatments you have been given. They'll also do an examination to check your muscle power, balance, co-ordination, reflexes and sense of touch.

There are two types of electrical tests that can check the function of the body's nerves and muscles. These tests are often done at the same time. They are not painful but might be a little uncomfortable.

- **Nerve conduction study (NCS)**

During this test, small metal wires called electrodes are put onto the skin. Tiny electric shocks then stimulate the nerves whilst a machine measures the speed and strength of the nerve signals.

- **Electromyography (EMG)**

During this test a tiny needle is put into the muscles through the skin where it can measure the electrical activity of the muscle.

The neurologist will also take blood samples which can help to understand what might have caused the PN and what type of PN you have.

Other tests might be suggested, depending on what your neurologist thinks is going on. These will be explained to you if they are needed.

Treatment

The treatment for PN will depend on what has caused it, the results of the tests and your symptoms. Treatment might not be needed if your symptoms are mild and there are no signs that the WM has got worse. However, it is important to continue with regular check-ups.

Depending on the severity of your symptoms, small changes like wearing sensible shoes, using a walking stick and some simple physiotherapy may help. However, if your symptoms worsen then your healthcare team may refer you for some additional treatment to help you manage anti-MAG neuropathy.

If the PN is painful, you can have treatments to dampen down the abnormally painful signals from the nerves. Nerve irritation pain doesn't usually respond to normal painkillers such as paracetamol. Your neurologist will be able to recommend the best pain relief to use.

If symptoms are getting worse quickly and affecting how you walk or use your hands and it is found that WM is directly causing the PN, then treating the WM can help. More information about these treatments can be found in the **Types of WM Treatment** section of this guide (page 14).

You can find more information about treatments for WM and associated conditions on our website:

www.wmuk.org.uk/your-journey-with-wm/wm-treatment/types-of-wm-treatment

Cryoglobulinaemia

Symptoms

- Blue tinge to hands and feet when cold
- Painful hands or feet when cold
- Skin rashes that are purple or red-brown
- Skin ulcers – holes in the surface of the skin
- Gangrene, which is when parts of the flesh die because of a lack of blood supply
- Swollen ankles and legs
- Joint pain

About Cryoglobulinaemia

Cryoglobulinaemia (often shortened to cryo) is a rare condition seen in fewer than 4% of people with WM. In this condition a type of abnormal antibody called cryoglobulins stick together when the body gets cold. The clumps of these antibodies get stuck in the coolest parts of your body, like your hands, feet, ears and nose. This can block the blood flow around your body. It doesn't matter how many cryoglobulins are in your blood, just having them can cause this disease.

Cryoglobulinaemia shares some similar symptoms to cold agglutinin disease (CAD), which is described on page 21 of this guide, and some people have both these conditions together.

Diagnosis

If you or your healthcare team suspect you may have cryoglobulinaemia they will ask about your symptoms and take blood tests – including a specific blood test to measure the amount of cryoglobulins in your blood. Unlike regular blood tests, your blood sample is kept warm until it gets to the laboratory, so it's important that your healthcare team are aware you are being tested for cryoglobulinaemia.

You will also have other blood tests that will check if anything other than WM has caused it. Cryo can also cause kidney damage so you may have blood tests to check the health of your kidneys.

Treatment

Because the cryoglobulins stick together in the blood when the body is cold, the easiest way to prevent it happening is to keep warm. This could include:

- Wearing more clothes, both in summer and winter
- Avoiding air conditioning where possible
- Avoiding cold food or drink

If your symptoms are severe or your blood tests show WM is getting worse, your healthcare team may decide that it's time to consider treatment for WM. This can reduce the cryoglobulin that your body is producing. More information about these treatments can be found in the **Types of WM Treatment** section of this guide (page 14).

AL amyloidosis

Symptoms

AL amyloidosis symptoms will be different, depending on the part of the body that has been affected by amyloid, an abnormal protein that builds up in the body.

If amyloid has built up in the heart, symptoms may include:

- Breathlessness
- Swelling of feet and hands
- Tiredness

Amyloid build-up in the kidneys may cause:

- Frothy urine
- Shortness of breath
- Tiredness
- Swollen ankles

If the digestive system has been damaged by amyloid, symptoms might include:

- Loss of appetite
- Weight loss
- Diarrhoea
- Nausea and vomiting

When the nervous system is affected by amyloid this can cause:

- Tingling or numbness in the hands and feet
- Tiredness
- Dizziness or fainting

About AL amyloidosis

Amyloidosis is a rare condition that affects the organs in your body. It occurs in up to 10% of people with WM.

Amyloidosis is caused when a protein called amyloid builds up in your body. Amyloid often builds up in the heart, kidneys, liver, spleen, nerves and the digestive system, and can stop these organs from working properly. There are different types of amyloidosis, many that are not related to WM. The type of amyloid that is linked to WM is called AL amyloidosis.

Diagnosis

Amyloidosis is rare and needs specialist care. In the UK, there is a National Amyloidosis Centre (NAC) based in London. If amyloidosis is suspected, you may be seen at the NAC, or your healthcare team might ask the NAC for advice or an opinion about your case. People can be referred to the NAC before a diagnosis has been made.

Several tests may be carried out to confirm a diagnosis. These may include:

- Biopsy

  A medical procedure that involves taking a small sample (called a biopsy) from the part of the body doctors think might be affected by the amyloidosis. The biopsy will be studied under a microscope to see if there is any build-up of amyloid proteins.

- SAP scan

  Serum amyloid P component (SAP) is a normal protein in the blood that sticks to amyloid. The SAP scan shows where SAP is present in the body and so where there is a build-up of amyloid. This scan is only available at the NAC in London.

Treatment

If amyloid has damaged your organs, it may be necessary to start chemoimmunotherapy treatment for your WM. This treatment will reduce the number of abnormal cells so that there are fewer abnormal light chains being made. This will prevent any further organ damage.

Some patients may also be offered a very intensive treatment called a stem cell transplant. It's a harsh and risky procedure, so you would need to be relatively fit, despite having WM, for this to be considered.

Treatments can work well and give a period of remission from amyloidosis. This is where the AL amyloidosis is not active or causing symptoms. However, it is quite common for the AL amyloidosis to come back. If this happens, more treatment will be needed. This may be the same as before, or a different combination of drugs might be used.

More information about these treatments, including chemotherapy and stem cell transplants, can be found in the **Types of WM Treatment** section of this guide (page 14).

Treatments can also be given to help control symptoms and complications caused by the amyloid deposits. This is called supportive treatment. Supportive treatment includes anti-sickness drugs, antibiotics, and water tablets (called diuretics).

If there has been a lot of damage to the kidneys, then kidney dialysis or a kidney transplant might be needed.

Useful to know

There has been a lot of research into new treatments for amyloidosis recently and the results so far are promising. However, these treatments are still being tested and are not widely available yet.

Bing-Neel syndrome (BNS)

Bing-Neel syndrome is a rare condition that **affects less than 1% of people with WM.**

Symptoms

- Headaches
- Tingling or numbness in hands or feet
- Problems with vision
- Seizures or fits
- Difficulty walking
- Loss of balance
- Weakness in arms and legs
- New memory problems
- Double vision, changes in hearing or swallowing or face muscle weakness

About BNS

BNS is a very rare condition which occurs in less than 1% of people with WM. It occurs when the abnormal white blood cells (B-cells) that cause WM are able to get into the nervous system and cause problems. This might affect the brain or spinal cord (central nervous system) or the nerves in the arms and legs (peripheral nervous system).

It is not fully understood how or why these abnormal B-cells are able to cross the protective layers – known as the blood-brain-barrier (BBB) and blood-nerve-barrier (BNB) – which normally protect nervous system tissue.

Once the abnormal B-cells are in the nervous system, they can build up in:

- the meninges, the protective and supportive membrane that covers the brain and spinal cord
- the brain or spinal cord tissue itself
- the motor or sensory nerves in the arms and legs

BNS can also cause a broad range of symptoms depending on the location of the abnormal cell build up in the nervous system. Some people can get symptoms when their WM is in remission. Others may get BNS symptoms at the same time as WM symptoms, or before they are aware they have WM.

Diagnosis

BNS can be difficult to diagnose and several tests can often be needed, depending on which part or parts of the nervous system are affected.

- Lumbar puncture

  If BNS is suspected, your doctor might look for the presence of abnormal WM B-cells in the spinal fluid that surrounds the brain and spine. The procedure to collect a small sample of this fluid from the lower back is known as a lumbar puncture. You can find more information about this procedure on the NHS website:

www.nhs.uk/conditions/lumbar-puncture

- MRI (magnetic resonance imaging) scan

  This type of scan uses magnets to look inside the body in detail. Sometimes, a special dye is injected into the blood stream so that the tissues and blood vessels show up more clearly.

- Nerve conduction studies and electromyogram (EMG)

  These electrical tests are used to gauge how well nerves are working in the muscles in the arms and legs.

- Brain or nerve biopsy

  If your health care team suspects that abnormal WM B-cells may be inside brain or nerve tissue they may need to take a sample of affected tissue. This would be done by a surgeon (usually a neurosurgeon). A brain biopsy is an operation performed under general anaesthetic but a nerve biopsy might be able to be done with just some local anaesthetic around the area to be sampled (usually the ankle). You can find more information about this procedure on the NHS website:

www.nhs.uk/conditions/biopsy

Treatment

BNS is very rare, so you might be referred to a specialist, or your current team may seek guidance from a specialist. Because it is so rare, there's isn't conclusive evidence about which treatment is most effective. The type of treatment you have will depend on your personal circumstances, symptoms, and how your WM is affecting you.

Treatments can include:

- Steroids – that can kill WM B-cells
- Chemotherapy – given as an individual drug or as a mix of different drugs
- Thiotepa – a type of drug that sticks to cancer cells, stopping them from reproducing
- Chemo-immunotherapy – which is a mix of two treatment types – chemotherapy and immunotherapy, which is sometimes used to treat WM
- BTK inhibitors – drugs that target certain parts of the cells that cause WM
- Radiotherapy – which uses radiation beams to kill the cancer cells
- Stem cell transplant – an intensive treatment that replaces damaged cells in your body with healthy cells

You can find more information about some of these treatments in the **Types of WM Treatment** section of this guide (page 14).

You can find more information about treatments for WM and associated conditions on our website:

www.wmuk.org.uk/your-journey-with-wm/wm-treatment/types-of-wm-treatment

Finding support

Being diagnosed with WM or one of the related conditions can come with a range of emotions. Sometimes it can be good to speak to people who understand what you're going through, to get advice or just to talk things through.

1–2–1 support

Speaking to someone on a 1–2–1 basis can really help – whether you have worries, aren't feeling yourself or have questions you wished you'd asked your doctor.

WMUK offers both emotional and clinical support. For all your questions about diagnosis, treatment and symptoms, you can call our Support Line.

The Support Line is staffed by an expert WM nurse, who is there to help you navigate the world of WM and can also signpost you to other resources or organisations that may be useful.

You can call the Support Line on: 0300 373 8500. Alternatively, you can get in touch via email anytime on: support@wmuk.org.uk

Support groups

Even if you have supportive friends and family, sometimes you might feel like they don't understand. Meeting people who are going through a similar experience to you can be a good way to feel less alone. Support groups do just this, bringing together people with WM who live in the same region or have similar experiences to share their stories and advice.

To find out more visit:

www.wmuk.org.uk/waldenstrom-macroglobulinaemia-support-groups

Online support

You might not feel comfortable talking face-to-face so we also run forums to allow people to chat online. These forums are full of people with different experiences of WM who offer friendly advice and support whenever you need it.

To find out more visit:

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-giving-you-support

Join our Facebook Group

We run a thriving Facebook group for people living with WM. There you can meet and chat with over 600 people, all in varying stages of their WM journeys and with a wide range of experiences.

We're here for **you.**

You can join here:

https://www.facebook.com/WMUKCharity

Sources and Acknowledgements

This booklet has been written, revised and edited by WMUK alongside both WM patient and clinical expertise. It has been signed off by the charity's Information Lead. We would like to thank our Patient Advisory Group (PAG) for their user input into this guide, as well members of WMUK's clinical advisory board (CAB) for clinical input.

For a full list of the sources used in our WM information, please email: info@wmuk.org.uk

We welcome all feedback on our resources. If you have thoughts you'd like to share, please email us on the email address above.

About WMUK

WMUK is the only charity in the UK focused solely on Waldenstrom's macroglobulinaemia (WM). Our vision is that people affected by WM live longer, good quality lives, being supported every step of the way by WMUK.

Through working with the WM community, we build support programmes that help to empower patients and their families so that they can live fulfilled lives. We organise meet-ups, conferences, virtual webinars and run a thriving forum which is a welcoming place for anyone needing a listening ear.

Our website and Support Line are also sources of reliable and accessible information, so that everyone affected by WM can get the answers and support they need, whenever they need it.

We also harness the power of data, providing researchers with the data they need to improve care and treatment for WM patients.

Find out more: wmuk.org.uk

Contact the WMUK Support Line and speak to an expert WM nurse: 0300 373 8500

For general enquiries call us on: 0300 303 5870

Other resources

From WMUK:

Visit our website for more in depth information about WM:

wmuk.org.uk/your-journey-with-waldenstroms-macroglobulinaemia

Call our Support Line anytime: WMUK is always here to support you and those close to you – including family members, friends and carers. You can call or email our Support Line (0300 373 8500 or support@wmuk.org.uk) for answers to your questions or simply if you need a listening ear. Our friendly, expert team are always here to help.

Connect with other people living with WM in your local area:

wmuk.org.uk/waldenstroms-macroglobulinaemia-giving-you-support

Find advice and support for friends, family and carers on our website:

www.wmuk.org.uk/friends-family-carers-wmuk

We're here for **you.**

Other resources

From other organisations:

Find out about the emotional support services offered by the Penny Brohn charity: pennybrohn.org.uk

Get mental health support from: mind.org.uk

Get free expert cancer care and support at a Maggie's Centre near you: maggies.org

Patient Information Forum

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