Diagnosed with Waldenstrom's Macroglobulinaemia?

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

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

You've picked up this booklet because you've been diagnosed with Waldenstrom's macroglobulinaemia (WM), or someone you know has.

You may be feeling lots of different emotions and have a lot of questions – we're here to help you understand what WM is and get you the answers you're looking for.

Most importantly, we want you to come away knowing that you're not alone. There is a thriving and positive community of people just like you, all living well and supporting each other through life with WM.

Whatever your situation and however you're feeling, we're here for **you.**

My healthcare team

Key contact

Name: ____

Role: ____

Contact details: ____________________________________

Job title / role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist or key worker	

We're here for **you.**

Contents

About this booklet

This booklet is designed for people who have just been diagnosed with WM, or their family and friends. It covers all the basics about WM, including what it is, how it's treated and how to live well with the disease. It also includes useful information about the new terms you might come across, and the different types of healthcare professionals you might meet.

Go through the booklet at your own pace. You might not want to read it all at once, or you may just read the sections that are relevant to you now. If you're looking for more in depth information on certain aspects of WM or related conditions, please refer to the 'Other resources' section at the end of this booklet.

Throughout the booklet you may see a ↖ icon. This tells you that you can find more in depth information on the WMUK website.

This booklet has been put together with input from expert healthcare professionals and people living with WM. However, it gives general guidance and should not replace the personalised advice and care given to you by your healthcare team.

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

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 that can help with symptoms and to stop it from developing
- 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

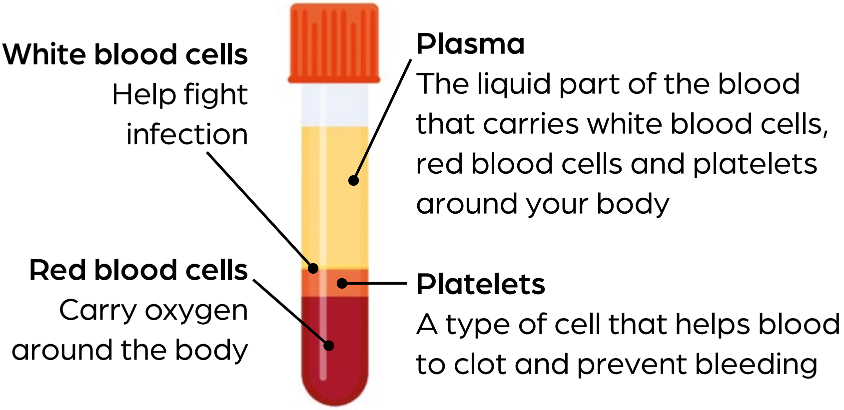
Don't worry – you're not alone if you're struggling to pronounce it. Most of us call it WM or simply Waldenstrom's, but if you do want to use the full name, it is said:

WALL-DEN-STROMS
MA-CRO-GLO-BEW-LI-NEE-MEE-AH

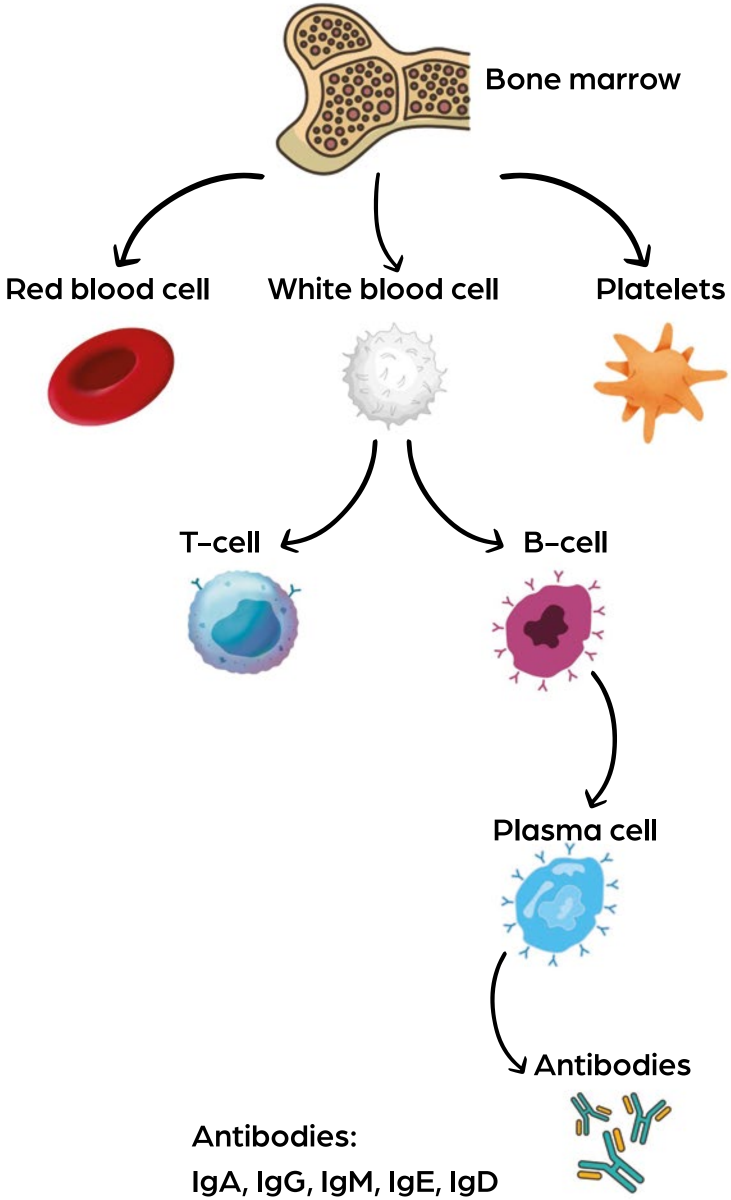
What causes WM?

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. Sometimes, the process goes wrong and the cells develop incorrectly, or abnormally.



Normal blood cell production



Antibodies:

IgA, IgG, IgM, IgE, IgD

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.

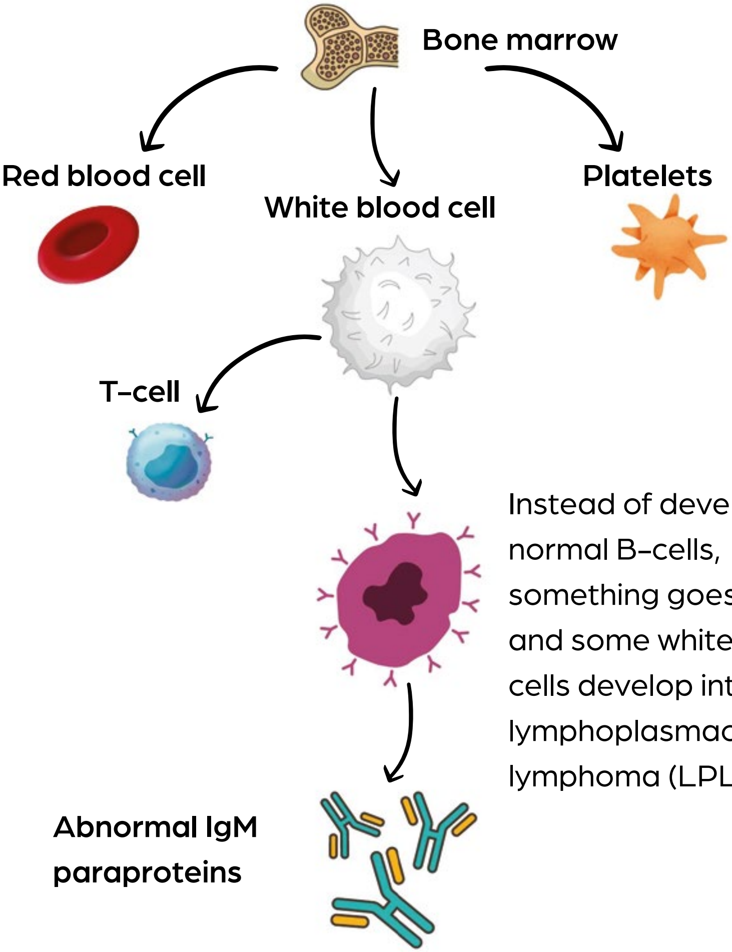
This means the healthy cells can't do their jobs properly, causing many of the symptoms people with WM feel.

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

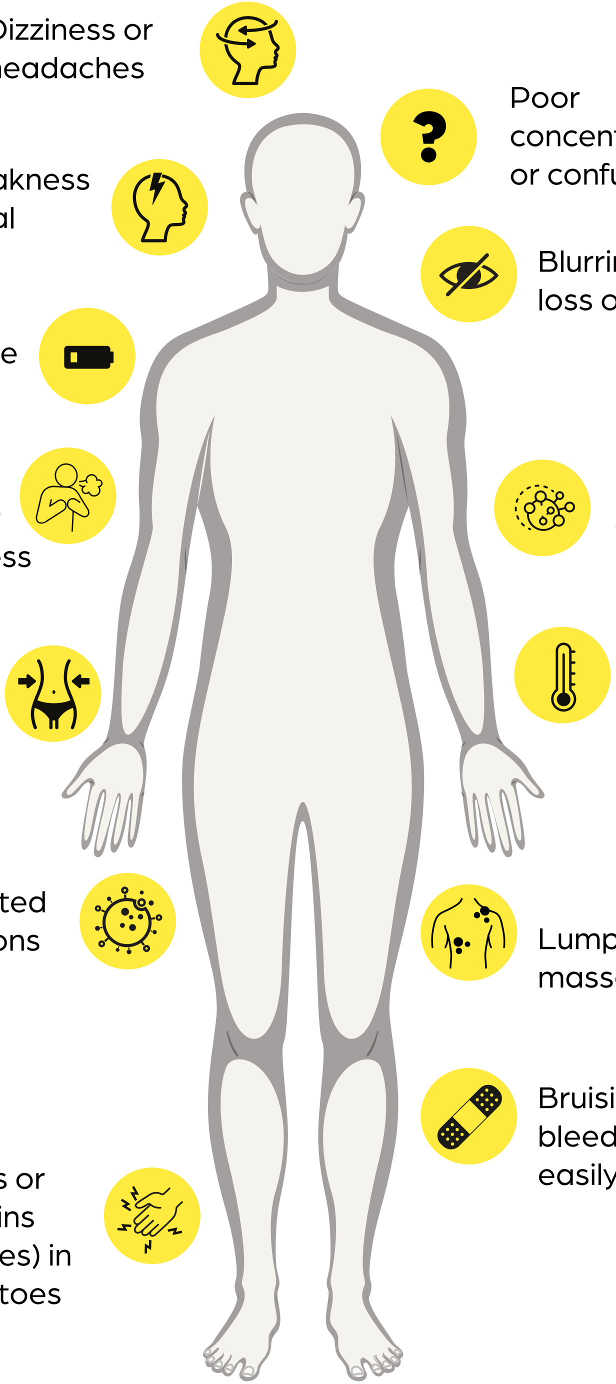
The abnormal cells can also produce antibodies (or ‘paraproteins’). In people with WM, these are the IgM antibodies, and the higher levels of them in your body can cause a range of symptoms.

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

WM symptoms & related conditions

You might have already felt some WM symptoms, prompting you to visit your doctor. However, for some people with WM, their diagnosis is a shock, and you might not have experienced any symptoms at all.

There are lots of different symptoms linked to WM and they vary from person to person. We've listed some of the most common below. Your symptoms are an important way for your healthcare team to monitor your WM, and decide if you need to go on treatment, or need further tests. So, it's important to discuss any symptoms you have, whether they appear on the list on the right or not.



Dizziness or headaches

Poor concentration or confusion

Fits or weakness in the facial muscles

Blurring or loss of vision

Fatigue

Swollen glands

Weakness or breathlessness

Unexplained weight loss

Fevers and night sweats

Repeated infections

Lumps or masses

Bruising or bleeding easily

Numbness or tingling (pins and needles) in fingers or toes

Sometimes, symptoms can be difficult to manage. If your healthcare team has decided you don't need treatment just yet, they can still help you manage your symptoms so you can continue to live well.

Ways you can manage symptoms yourself are:

- **Keep a symptom diary** that records your symptoms and how much they are affecting you and your day-to-day life. This can help both you and your healthcare team to understand what might cause certain symptoms or make them worse
- **Plan ahead** – *"I have learnt to have back up plans and activities ready from when bad days hit… things that don't require much energy or concentration."*
  – Vern, WM patient
- **Stick to a healthy diet** and keep as active as you can
- **Avoid foods that trigger night sweats**, like caffeine or spicy food, and wear loose clothing in layers

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-symptoms

Symptoms might not be caused by your WM, but instead a related condition that needs treatment. Make sure you mention any symptom to your healthcare team, no matter how mild it might seem or if you think it isn't to do with your WM.

Conditions related to WM include:

- **Hyperviscosity syndrome (HVS)** – this is when your blood becomes thicker than normal, causing symptoms like headaches, dizziness and changes in vision
- **Cold agglutinin disease (CAD)** – this is when some parts of your blood cells react differently when you get cold, causing anaemia
- **Bing Neel syndrome (BNS)** – a very rare condition where your abnormal WM cells enter your spinal cord and brain, causing symptoms that affect your central nervous system
- **Peripheral neuropathy (PN)** – when abnormal cells target part of your nervous system, damaging it and causing symptoms like tingling or 'pins and needles' in your feet or hands, numbness and problems with balance or co-ordination
- **Cryoglobulinaemia** – some people with WM have higher levels of a type of cell called an antibody that is sensitive to cold temperatures, causing symptoms like pain or blue tinged skin on their hands and feet when they're cold
- **Amyloidosis** – a rare complication where parts of abnormal cells develop incorrectly and build up in your organs, meaning they can't work properly. Symptoms vary depending on what organs are affected

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-related-conditions

Active monitoring

You may have been told that you're not having treatment right away. This may come as a surprise and might even worry you. However, this doesn't mean that your healthcare team are ignoring you. Instead, they are putting you on a treatment plan called 'active monitoring'.

Active monitoring (sometimes called 'watch and wait' or 'active surveillance') is a safe and recommended way to care for people with slow-growing cancers like WM.

There isn't any evidence to show that being treated earlier has any benefits. Treatment itself can have some harsh side effects, which can be long lasting. By putting you on active monitoring, your doctor is saving treatment for when it can have the maximum impact. Many people with WM live well for years whilst on active monitoring.

If anything changes between your check-ups, you don't need to wait until your next appointment. Contact your team and let them know your concerns – they may want to see you earlier.

Whilst on active monitoring, you'll have regular check-ups with your healthcare team, where you'll have blood tests and a chance to talk about how you're feeling, including any symptoms or concerns you have.

These check-ups will help your doctor understand how your WM is behaving, and whether it's time to start treatment. They also give your healthcare team the chance to pick up on any other conditions, and ensure you get the right treatment for this.

As someone who is newly diagnosed, these check-ups will be fairly frequent – around every 3 months. As time goes by, and if your WM remains stable (doesn't change), your healthcare team may decide to lengthen the time between appointments.

WMUK have produced an 'Active Monitoring Checklist' with patients and healthcare professionals to help you and your healthcare team manage this period of time without treatment. You can find it at the centre of this booklet.

Blood tests

Blood tests play a big part in helping your healthcare team diagnose and monitor your WM. You'll have blood tests taken regularly at check-ups and whilst you're on treatment, so that your healthcare team can understand how your WM is behaving – is it stable, growing or decreasing?

Your healthcare team will be looking out for different things in your blood tests:

- **IgM levels** – people with WM produce an abnormal quantity of an antibody called IgM. The higher the levels of IgM in your blood, the more likely you are to feel symptoms and it might be a sign that the disease is progressing and that you need treatment
- **Full Blood Count (FBC)** – this checks the levels of the different types of blood cells. If these levels go down, you may have developed another condition related to WM. Lower levels of red blood cells can mean you have anaemia, and low platelets might indicate you have thrombocytopenia. By picking these up, your doctor can offer you therapies to treat these conditions and help you feel better
- **Specialist tests** – if you have a specific set of symptoms, your doctor might suspect a condition related to WM. For these, they may order more tests to help diagnose you so that you can get the right treatment

Although blood tests are important, they don't paint a full picture. 'Normal' results vary from person to person. Two people could have the same result, but they might not both need treatment. For this reason, it's important to not put too much emphasis on them.

Instead, be sure to report your symptoms to your healthcare team and be honest about how you feel. Symptoms play an equally important role in helping your doctor decide if you need further tests or treatment.

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-after-diagnosis

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 6 cycles of chemotherapy, but sometimes this is shortened or doses reduced.

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.

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-targeted-treatment

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.

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-stem-cell-transplants

Your healthcare professionals

When you're diagnosed with WM, you'll have a whole team of healthcare professionals who work together to plan your care. These healthcare professionals specialise in different areas of your care, and together they are called a multidisciplinary team.

You might have already met some of these people whilst you were being diagnosed. Some healthcare professionals you might not ever meet, although it is good to know who they are and what role they play.

Pull out resource ▲▲▲

Things That Are Important To Me And My WM

An Active Monitoring checklist for people with Waldenstrom's macroglobulinaemia

Pull out resource ▲▲▲

Active monitoring (AM) is when your healthcare team monitor your WM, rather than treating it right away. You may hear it called 'active surveillance' or 'watch and wait'.
This checklist is designed to outline the essential topics which should be discussed with your clinical team throughout your Active Monitoring care, and can be used within your appointments alongside your clinician.

Some of the terms used in the checklist may vary depending on where in the UK you live, if you have any questions or would like any further information on Active Monitoring then please contact us on support@wmuk.org.uk

What will AM consist of?

☐ I understand how often I will have monitoring appointments with my healthcare team

☐ I understand and am satisfied with the format of my future appointments (e.g., face-to-face, telephone, virtual)

☐ I understand what tests will need to be performed to monitor my condition and how often these will be performed

☐ I understand that WM can affect my immune system and therefore I should take reasonable precautions to avoid infection, including ensuring my vaccinations are up to date

☐ I feel that I have been given enough information about my condition at this time

Additional support during AM

☐ I know the contact details of the Clinical Nurse Specialist (CNS), or key worker, and understand what support they can offer me during active monitoring

☐ I have discussed the roles of other members of the Multidisciplinary Team (MDT), and the support which they may be able to provide to me if I need it

☐ I have been given information about how to contact or access information from patient support groups/ charities such as WMUK

Contributing to WM research

☐ My clinical team has made me aware of the Rory Morrison Registry and discussed the inclusion of my data

☐ Clinical Trials have been discussed with me and I have been signposted to where I can find more information

☐ I have been signposted to the myWM app

My lifestyle

☐ I understand the impact of my general wellbeing on my condition and the importance of keeping as well as I can

☐ I have discussed the importance of regular and appropriate exercise as it relates to my general wellbeing and my condition with my WM care team

☐ I have discussed with my clinical team, the importance of ensuring any other medical issues I may have are being addressed and managed well by my GP or other healthcare provider

☐ I have discussed any other issues which are affecting me

If you are unable to tick any of the boxes above, please discuss your concerns or questions with your clinical team

For more information

wmuk.org.uk or call the WMUK Support Line: 0300 373 8500

☐ I feel that I have been given enough information about what to expect during the active monitoring phase of my treatment

My Waldenstrom's macroglobulinaemia

☐ My current symptoms have been discussed during this consultation

☐ I understand that if I experience any of the below symptoms between my appointments, I should contact my clinical team:

- Dizziness or Headaches
- Fatigue
- Weakness or Breathlessness
- Unexplained weight loss
- Fevers and night sweats
- Bruising or bleeding easily
- Repeated infections
- Poor concentration or confusion
- Blurring or loss of vision
- Swollen glands
- Lumps or masses
- Numbness or tingling (pins and needles) in fingers or toes

Clinical oncologist or haematologist – a doctor who specialises in treating people with cancer using radiotherapy, chemotherapy and other cancer drugs.

Haematologist – a doctor who specialises in treating people with blood disorders, including blood cancers like WM.

Clinical Nurse Specialist (CNS) – an expert nurse who specialises in a specific area of health, like haematology (blood disorders).

Pathologist – a doctor who studies cells and body tissues. These doctors help to interpret your blood tests and biopsies.

Pharmacist – a professional who makes sure you're receiving the correct treatment, in the dose that's right for you.

Radiographer – a professional who carries out X-rays, MRI and CT scans.

Radiologist – a professional who specialises in looking at X-rays, MRI and CT scans and what they mean.

At the beginning of this booklet, there is space to record the names and contact details of your key healthcare professionals.

Your key worker

Every person living with cancer in the UK should be given a key worker, who is their central contact. This person is there to help you navigate the healthcare system, answering any questions you have, or raising your concerns.

When you're diagnosed, you should have been told who your key worker is and given their contact details so you can get in touch with any questions or concerns. A lot of the time, your key worker is your CNS.

If you weren't given the contact details of your key worker, or can't remember if you were told about them, then contact your healthcare team. Having a key worker to contact will help make your care smoother, as well as providing reassurance when you need it.

Getting a second opinion

WM is a rare form of cancer, and so it needs to be treated by someone with experience and expert knowledge. There aren't any specialist centres for WM in the UK, but there are a number of specialist clinicians who are up to date with the latest treatments and recommendations. You may be referred to one of these specialists, or you might continue your treatment at your local hospital, with your healthcare team receiving advice from the nearest specialist.

The guidelines for treating WM state that doctors should refer their WM patients to expert clinicians. When this isn't possible – for example you can't travel – they should work alongside experts to ensure you're getting the most up to date care.

If you have concerns about your care, you can request a second opinion. This is where your current doctor refers you to another doctor. The second doctor will look at your notes and history and give their opinion on the next steps for your care. You can either then choose to be treated by the second doctor, or return to the care of your current doctor, reassured that you're receiving the best care available.

Living well with WM

You might not be feeling well as you read this leaflet, especially if you have symptoms that have affected your quality of life. However, with treatment and by looking after yourself physically and mentally, you can live well alongside your WM.

Many people get back to the activities they once enjoyed, whether these are sports or social occasions. Speaking to your healthcare team can help you understand how you might be able to get back or continue with your favourite activities and lead a full life.

Here, we share some general advice on keeping healthy.

Eating well

By eating a balanced diet, you can give your body all the nutrients it needs to work well. This can help you feel stronger, improve your energy levels and help your immune system.

For most people, a balanced diet is made up of:

- At least five portions of fruit and vegetables every day
- Starchy foods (carbohydrates) like pasta, bread and potatoes. Wholegrain types are better
- Some protein–rich foods like lean meat, eggs, pulses, nuts and fish
- Some dairy products like cheese, milk and yoghurt

Limit the following foods:

- Foods that are high fat and sugar. These carry no additional vitamins and minerals
- Processed and red meats
- Foods that are high in salt

Some people find that they lose or gain weight due to their symptoms, or as a side effect of treatment. If you're concerned about your weight – too high or low – speak to your healthcare team. They'll be able to give you advice, or refer you to a dietician who can help.

Exercise

Physical activity has lots of benefits. It can help to reduce fatigue, improve your mental health, control your weight and blood pressure, and reduce your risk of heart disease. It can also help to manage some treatment side effects.

Mild exercise like gentle walking, gardening and household chores can really add up. The guidelines are to do 150 minutes of moderate activity every week. These can be in bursts of just 10 minutes.

You may find that your symptoms have got in the way of your usual activities. This can be frustrating or saddening. However, it's important to do what you can.

Some ways you can manage exercising around symptoms are:

- **Plan your exercise** – if you know you often have more energy in the morning, then schedule in a gentle morning walk
- **Build up gradually** – if you're not used to exercise or haven't exercised for a while, start in small 5–10 minute chunks and gradually build up the time from there
- **Try mild exercises** like household chores (gardening, hoovering), walking or yoga
- **Adapt activities you enjoy doing.** For example if you are a keen cyclist but can't manage hills, swap your old bike out for an electric one to help you on the inclines
- **Get expert guidance.** If you're unsure about starting a new regime, your doctor or physiotherapist will be able to help you put together a plan for your specific needs. This is especially important if you have symptoms that make exercising more difficult, like peripheral neuropathy, which can affect your balance

> Many people feel much better after they've finished treatment, and find they can return to the activities they used to enjoy.

Mental health

There isn't a right way to feel about your diagnosis. You're not alone if you're struggling with your feelings and emotions – many WMers report that they are struggling or have struggled with their mental health because of their diagnosis.

- **Talking to others** – family, friends, a healthcare professional or with other people living with WM – can sometimes lighten the load
- As well as talking about your feelings and thoughts, don't be scared to **ask for practical help**. Getting help with household chores, for example, can ease the pressure when you have hospital visits, and help you to take the rest you need
- **Looking after yourself physically** is just as important for your mental health as it is your physical health, even if it is a short walk around the garden or some gentle yoga

If you have been struggling for a long time, feel very anxious or think you might be depressed, speak to your healthcare team. There are different services and treatments available to you, and your doctor will be able to advise and refer you where necessary. We've listed some relevant organisations that might be able to offer you support in the 'Other resources' section at the end of this booklet.

Work

Everyone's WM experience is different, and this is the same when it comes to working with WM. How your WM affects your working life depends on factors like your WM symptoms, whether you're on treatment and what your work involves. Whatever your situation, it's important to know that as someone living with cancer you have rights in the workplace.

You don't have to tell your employer that you have cancer. However, as someone living with cancer, you are classed as having a disability. This means that you can't be treated less favourably than you might be if you didn't have WM.

Your work must also make what are known as 'reasonable adjustments'. Reasonable adjustments are changes your employer must make to remove or reduce disadvantages you face in carrying out your role because of your WM. This could be allowing you to work from home or modifying your role so you don't have to spend as much time on your feet. If your work doesn't know about your diagnosis, they won't be able to help you in these ways.

www.wmuk.org.uk/living-well-with-waldenstroms-macroglobulinaemia

Vaccinations

As someone with WM, you're more at risk when it comes to viruses and infections. This is because the blood cells that help fight infection in your body haven't developed correctly. With fewer cells to fight infection, you are more at risk of becoming seriously ill or developing complications from illnesses like the flu.

Vaccines play a big role in helping to protect you against diseases, and giving you a better chance of avoiding complications.

You are eligible for:

- Seasonal flu vaccine
- COVID-19 vaccine (including all extra doses/boosters for the extremely clinically vulnerable). You can read more about COVID-19 vaccines and other ways to protect yourself here: www.wmuk.org.uk/waldenstroms-macroglobulinaemia-covid-19
- Pneumococcal vaccine in the form of pneumococcal conjugate vaccine (PCV13 or Prevenar 13), followed by pneumococcal polysaccharide vaccination (PPV23 or Pneumovax) at least 2 months later (these protect against pneumonia)
- Shingles vaccine (a non-live version called Shingrix) is available to people with WM aged 50 and over. You get 2 doses of the vaccine, with a minimum of 2 months between each dose

There are some vaccines which you can't have. These are 'live' vaccines, that contain a small amount of the disease they're protecting against. These vaccines can make people with WM ill.

Live vaccines include:

- Polio
- Herpes zoster (a live shingles vaccine)
- Yellow fever

Although these listed vaccinations are recommended for people with WM, you should always discuss any vaccinations with your healthcare team who can ensure they are safe for your individual needs.

Finding support

Sometimes it can feel like you are alone in your diagnosis. This isn't true. Whether it's family, friends or the thriving WM community, there is always someone to talk to, to share worries or get advice.

Telling people about your diagnosis

This is often something people worry about when they first get diagnosed. It can be hard, especially with loved ones. However talking to people you know and trust can be a big help in feeling less isolated by your diagnosis.

www.wmuk.org.uk/waldenstroms-macroglobulinaemia-newly-diagnosed

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.

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

Online support

You might not feel comfortable talking face-to-face with strangers, and this is absolutely fine. 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.

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

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 a 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

WM glossary

Active Monitoring – *this is when your healthcare team monitor your WM without treating it. It is a safe and recommended way to treat slow-growing cancers like WM.*

Amyloidosis – *a rare complication where parts of abnormal cells develop incorrectly and build up in your organs, meaning they can't work properly. Symptoms vary depending on what organs are affected.*

Anaemia – *a condition caused by a lack of healthy red blood cells in your body. Symptoms include fatigue, breathlessness, headaches and pale skin.*

Antibodies – *produced by B-cells (a type of white blood cell) to fight infection in the body. Also known as immunoglobulins.*

B-cell/B-lymphocyte – *a type of white blood cell that develops to fight infection. In people with WM, B-cells develop incorrectly, causing the common symptoms of the disease.*

Bing Neel syndrome (BNS) – *a rare condition where your abnormal WM cells enter your spinal cord and brain, causing symptoms that affect your central nervous system.*

Bone marrow – *the tissue found in the centre of your largest bones where blood cells are created. WM is a cancer that starts in the bone marrow, when B-cells develop incorrectly.*

BTK Inhibitor – *a relatively new type of treatment for WM. They target a certain part of the WM cells and block them, killing the cells.*

Chemotherapy – *a type of drug, or combination of drugs that kill cancer cells.*

Cold agglutinin disease (CAD) – *this is when some of your blood cells react differently when you get cold, causing anaemia.*

Cryoglobulinaemia – *some people with WM have higher levels of an antibody (type of cell) that is sensitive to cold temperatures, causing symptoms like pain or blue tinged skin on their hands and feet when they're cold.*

Full Blood Count (FBC) – *a type of blood test that checks your levels of red blood cells, white blood cells and platelets.*

Hyperviscosity syndrome (HVS) – *this is when your blood becomes thicker than normal, causing symptoms like headaches, dizziness and changes in vision.*

Immune system – *this system protects your body from infection. Certain white blood cells – lymphocytes – recognise the cells that belong in your body and try to get rid of any that don't, like germs. In people with WM, a type of lymphocyte – the B-cells – start to develop incorrectly. This means that the immune system in people with WM doesn't work as effectively.*

Immunoglobulin – *another word for antibody. These cells fight infection in your body. There are five types of immunoglobulin: IgM, IgG, IgA, IgE and IgD. In people with WM, the body overproduces IgM, causing the common symptoms of the disease.*

Immunoglobulin M/ IgM – *a type of antibody produced by B-cells. IgM is the largest of the five types of antibody, and it helps the body fight infections. In people with WM, the body produces abnormal quantities of IgM, making the blood thicker and leading to some of the symptoms people with WM feel. Your healthcare team monitor the levels of IgM in your blood to help diagnose and monitor your WM.*

Lymphocyte – *a type of white blood cell that acts as your immune system's memory. If you have had an infection before, your lymphocytes will quickly recognise and fight the infection again. Lymphocytes are an important part in giving you immunity. There are three types of lymphocyte: B-cells, T-cells and natural killer (NK) cells. In people with WM, the B-cells (or B lymphocytes) develop incorrectly.*

Lymphoma – *a type of blood cancer that develops in the lymphocytes (a type of white blood cell). There are many different types of lymphoma, affecting different types of lymphocytes and different parts of the body. WM is a rare type of lymphoma.*

Lymphoplasmacytic lymphoma (LPL) – *a rare type of lymphoma where B-cells (a type of white blood cell) develop incorrectly. Although WM and LPL are often used to mean the same thing, they are different. WM is a type of LPL. Both people with LPL and WM will have abnormal B-cells. However people with other types of LPL do not have the high levels of IgM that people with WM have.*

Paraprotein – *the immunoglobulins (antibodies) that are produced in high quantities by abnormal white blood cells. In people with WM, these are the antibodies called IgM. This IgM is known as a paraprotein and measuring it can help your healthcare team monitor your disease.*

Peripheral neuropathy (PN) – *when abnormal cells target part of your nervous system, damaging it and causing symptoms like tingling or 'pins and needles' in your feet or hands, numbness and problems with balance or co-ordination.*

Plasma – *a liquid in the blood that carries red blood cells, white blood cells and platelets.*

Platelets – *a type of blood cell that stops bleeding. When you have WM, these cells can be crowded out by abnormal white blood cells. This means you might bruise easier and have unexplained bleeding.*

Red blood cells – *a type of blood cell that carries oxygen around your body. In people with WM, healthy red cells can be crowded out by abnormal white blood cells, which can cause WM symptoms like anaemia.*

Remission – *when the abnormal cells causing your WM have been significantly reduced, minimising or stopping the symptoms. The aim of WM treatment is to put your WM into remission.*

Stem Cell Transplant – *a type of treatment that replaces damaged cells in your body with healthy cells. It is an intensive treatment that is only offered under certain circumstances to treat WM.*

Thrombocytopenia – *a condition that can develop when your body isn't producing enough platelets, leading to unexplained bruising and bleeding. In people with WM this can happen because healthy platelets are crowded out by abnormal white blood cells.*

White blood cells – *a type of blood cell that helps fight infection. There are many types of white blood cells, including B-cells. In people with WM, it is B-cells that develop incorrectly.*

Sources and acknowledgements

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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.

This is the 2nd edition of this booklet, published in January 2025. The next review date is scheduled for January 2027.

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 through our patient registry. This world-leading programme involves hospitals and patients, 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 a nurse:
0300 373 8500

Call us: 0300 303 5870

We're here for **you.**

Other resources

From WMUK:

More in depth or specific information:
wmuk.org.uk/your-journey-with-waldenstroms-macroglobulinaemia

Leaflets are available to download and order:
wmuk.org.uk/wmuk-library

WMUK Support Line: 0300 373 8500
support@wmuk.org.uk

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

From other organisations:

Waldenstrom's macroglobulinaemia:
Fast Facts for Patients – UK Edition Download here:
wmuk.org.uk/wmuk-library

Emotional support: Penny Brohn pennybrohn.org.uk

Mental Health support: mind.org.uk

Practical support: Maggies Centres maggies.org

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