Welcome to

Wmuk

Registered as a charity in England
and Wales (1187121)
A company limited by guarantee in
England and Wales (12358324)

About WMUK

WMUK is the only charity in the UK focused solely on Waldenstrom's macroglobulinaemia (WM), a rare type of blood cancer.

Our vision is that people affected by WM live longer, good quality lives, being supported every step of the way by WMUK

Our goal is to be the informed voice of WM in the UK

Our values

These define who we are as an organisation, how we treat others and expect to be treated:

- Caring: we let others know we are always there for them and appreciate that everyone is different
- Collaborative: we seek connections, start conversations and build relationships, working together to solve problems
- People first: we do everything we can to equip, empower and challenge our people to accomplish great things on a regular basis
- Learning: we appreciate there is no end to knowledge and always chase it, in the pursuit of doing things better

As a charity, we put WM patients, families, friends and carers at the heart of everything we do, ensuring their voice is represented throughout our projects and at every level of the organisation.

WMUK's Strategy

Our strategy was put together with input from people with WM and other key stakeholders in 2023. The strategy is underpinned by four key strategic pillars.

Expert voice	**Data**	**Empowering patients**	**Financial sustainability**
Be the expert voice of WM, the most credible leading edge source	Harness knowledge, data and evidence to drive equitable access and improve patient outcomes	Empower patients to live well with WM and support them throughout their experience	Be a financially viable organisation with a strong foundation for achieving our goals

You can read our full strategy here

WMUK's Theory of Change

It's important to us to not only have a strategy, but a plan on how to attain our goals. Our Theory of Change lays out how we intend to create change in the environment we operate in, and putting our stakeholders' needs at the heart of that change.

Who are we?

WMUK is a community, and we have a number of committees that help form strategy and guide the various arms of our work. These are:

- Patient Advisory Group (PAG) – a group of volunteer patients with a variety of backgrounds and experiences, PAG plays a vital role in shaping the WM community by providing valuable feedback and input on WMUK's projects and information. They ensure the patient voice remains central to WMUK's strategy and initiatives.
- Board of Trustees – this elected group of individuals are responsible for the governance and strategic direction of the organisation.
- Staff team – a core group of highly-skilled and experienced professionals who are essential in ensuring the charity runs smoothly and effectively, making the significant impact to the WM community

About Waldenstrom's macroglobulinaemia (WM)

Here you can find some basic information about WM, as well as resources to help you learn more. Our Support Services team are experts in WM and can provide further information and answer questions.

Key information

- Waldenstrom's macroglobulinaemia (WM) is a rare form of blood cancer
- It is one type of a family of blood cancers known as non-Hodgkin lymphomas
- There is no precise prevalence data for WM in the UK. However, it's estimated that about 400 people are diagnosed with WM every year, and around 4,000 people are living with it in the UK
- It has been traditionally seen as disease of older men. However, our data shows that more women than previously thought are living with the disease, likewise with people under the age of 65
- Many people live for years, if not decades, with WM
- Symptoms are many and vary in degree. Some people have many symptoms, whereas other will only experience one or two. They include: fatigue, weakness, breathlessness, tingling in fingers and toes, unexplained weight loss, fevers and night sweats, swollen glands, poor concentration, confusion, bruising or bleeding easily, vision problems, dizziness, headaches, and fits

Diagnosis

- WM is diagnosed by bone marrow biopsy, which shows the cancer cells and levels of them. People will also have other tests, such as blood tests and sometimes scans
- The route to diagnosis for many patients is long and often stressful
- Due to the nature of symptoms, which can vary from patient to patient, and the rarity of the disease, many people often have to visit their GP multiple times and go through a battery of tests before their WM is picked up
- This can lead to patients and families starting their WM journey from a place of stress and exhaustion, and even lead to a distrust in the health services
- We have evidence that some patients are not being told the exact nature of their disease, with more general – inaccurate – terms being used. This means they're unable to find the information and support they need.

Treatment

- WM is a slow-growing cancer, meaning many people don't need treatment right away, going onto something called 'active monitoring' (sometimes called 'watch and wait' or 'active surveillance') where their healthcare team will regularly monitor their cancer to see if it is growing and how the person's quality of life is affected by symptoms. This can help them decide, along with the patient, when best to start treatment.
- There is no cure for WM. The aim of treatment is to get rid of as many cancer cells as possible, putting patients into full or partial remission (when there are fewer cancer cells in their blood, and therefore an improvement in symptoms).
- However, there is currently no treatment that can get rid of all the cancer cells, meaning WM and its symptoms will eventually come back; the person affected will need more treatment.
- Treatment options in the UK are limited, with chemotherapy the go-to first-line treatment for most patients. Second-line treatment can be chemotherapy or a new type of treatment that targets a part of the cancer cells, called a BTK inhibitor. There is unequal access to BTK inhibitors across the UK.
- There are clinical trials for further treatment for WM. However getting new treatments approved for use on the NHS in such a small patient population has been traditionally difficult.

You can find more information about WM in our booklet for patients and families facing a new diagnosis here. Our website also has more in-depth information on WM.

Living with WM

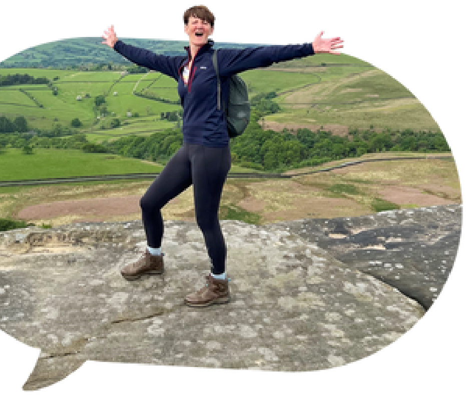
The nature of WM means that every person's experience is different, with people receiving different levels of care, having different symptoms at different stages, and even being able to access different treatments. However, there are broader themes, reported to us anecdotally and through our patient services:

- Living with WM can be an isolating experience, due the rarity and little public awareness
- There's lack of information on WM, with most patients reporting not receiving any take home information about the disease upon diagnosis, leading to worry, confusion and stress at an already difficult time
- Patients are more likely to report positive mental health impacts of a diagnosis than family, friends and carers, highlighting the unseen burden loved ones take on
- Overall patients and loved ones report high levels of anxiety and worry, especially those on active monitoring, who report increased worry around the time of check ups

You can read more about what patients and loved ones tell us about living with WM in our Big WM Survey results.

How WMUK supports the WM community

As a small organisation, we focus on the programmes that will have the most impact, using data and patient experience to identify gaps in care and focus our strategy.



Empowering patients and loved ones through support

- WMUK's Support Line is the only nurse-led support line for people affected by WM in the world. Our nurses provide practical and emotional support to patients and loved ones, giving them the reassurance and confidence they need to advocate for their own care and live well with WM
- The line is open Monday-Thursday 9am-5pm
- People can get advice by calling or emailing: 0300 373 8500 or support@wmuk.org.uk
- Our Buddy Service pairs up people living with WM with a trained, volunteer Buddy also living with WM, meaning people can access 1-2-1 peer support in a safe and supportive environment
- Drop-in sessions with a Support Line Nurse provide an informal way to talk to our nurse and others affected by WM, bringing people together to help them feel less isolated and more informed
- We support 15 volunteer-led support groups across the UK that bring people together online and in-person to help people feel less isolated
- We organise in-person Patient Summits that bring experts in healthcare to the WM community, as well as giving people the opportunity to meet others in similar situations face-to-face

Expert and reliable information giving people the tools they need to advocate for their own care

- We're addressing the significant lack of specific WM-information through the production of online and printed information
- Our Newly Diagnosed Guide was the first accredited booklet on WM for patients in the UK and is now in its 2nd edition. It can be <u>viewed here</u>
- Our website has comprehensive and ever-expanding information on WM and related conditions
- In March 2025, we launched the UK's first clinical trials hub for WM, which includes a searchable database of all the trials involving people with WM, giving patients the information they need to discuss with their healthcare team
- Our webinar series invites experts from an array of fields, focusing holistically on living well with WM

Education for Healthcare Professionals to create more equal care

- The first step in addressing health inequalities is ensuring that those caring for people with WM have all the tools they need to provide the most up to date care and guidance
- We run Nurse Study Days to give nurses vital information on this rare condition, and ensure they know to signpost patients and families to information and services
- We are creating a CPD-accredited nursing module on WM, to give nurses even more opportunities to learn.

Creating step changes in patient pathways and care through policy and advocacy

- Our Active Monitoring Checklist is the first of its kind, and is the result of collaboration across the WM community. It provides a framework to empower patients and healthcare professionals, with the aim of ensuring consistent care for WM patients on active monitoring, no matter where they are in the UK
- We work in conjunction with a number of alliances such as the Blood Cancer Alliance and Cancer52, ensuring that the WM voice is heard at a policy level
- We build relationships with key stakeholders in WM and the wider cancer and blood cancer community to raise concerns of the WM community and ensure their voice is heard

Using data to drive change

- We collect data that is patient-centric and that focuses on areas that patients tell us is important
- We use data to focus our work, identify gaps in care, and evaluate our impact and progress

Raising funds to create lasting and meaningful change

- Fundraising is a vital park of our work - we receive no statutory funding and therefore rely on voluntary donations from individuals, fundraising and grant-giving organisations
- We aim on two big individual asks a year, most notably the Big Give in December, where donations are doubled by generous donors
- We support fundraisers who organise events and take on challenges
- The funding climate in very competitive, meaning it is particularly challenging for a small organisation with limited resource and no in-house fundraising staff.
- Fundraising is therefore the responsibility of everyone in the organisation
- Building and leveraging networks and relationships is key to ensure significant and sustained funding for the charity's future.

How *you* could help people with WM

We're looking for a range of talented, resourceful and passionate people to help us create change for this small, and often overlooked, community. If you are someone with:

- expertise in data, particularly accessing, navigating and analysing health datasets
- skilled in collecting and using patient-focused data like PROMs or other quality of life data to create evidence for change
- experience in fundraising, successfully creating diverse income streams in a challenging environment
- experience of managing charity governance, either professionally or as a trustee or committee member
- knowledge of creating change and influencing at policy level, particularly in healthcare
- experience in navigating and influencing healthcare systems and institutions like NHSE, DHS, NICE or SMC
- a background in clinical research, ideally in the rare disease or cancer space
- or you feel you have skills or experiences not listed that could help us achieve our aims

... we'd love to hear from you.

Contact us:

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0300 303 5870

Find out more about getting involved with our charity

info@wmuk.org.uk

wmuk.org.uk

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