



MGUS (Monoclonal gammopathy of undetermined significance)

Your questions answered

**Blood
cancer
UK**

Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.



Call free on **0808 2080 888**

(Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm
and Saturday and Sunday: 10am to 1pm)

Email **support@bloodcancer.org.uk**

Visit **bloodcancer.org.uk**

Talk to others **bloodcancer.org.uk/our-forum**

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

Key facts about MGUS

MGUS is a blood condition that affects blood cells called plasma cells. It's important to know that:

- MGUS is not in itself a type of blood cancer.
- MGUS does not usually have symptoms and shouldn't affect your daily life.
- There is a small risk that MGUS can develop into a type of blood cancer, but this is rare.

This booklet will help you explain to family and friends what MGUS is and what it means for you. Some healthcare professionals may not be familiar with MGUS, so you may also find it helpful to take this booklet to medical appointments.

We have more information about MGUS online at bloodcancer.org.uk/mgus

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Please do get in touch if you would like to speak to someone about your diagnosis. We get lots of calls from people with MGUS and we're here to offer information and support when you need it.

Tanya, Support Services
Officer at Blood Cancer UK



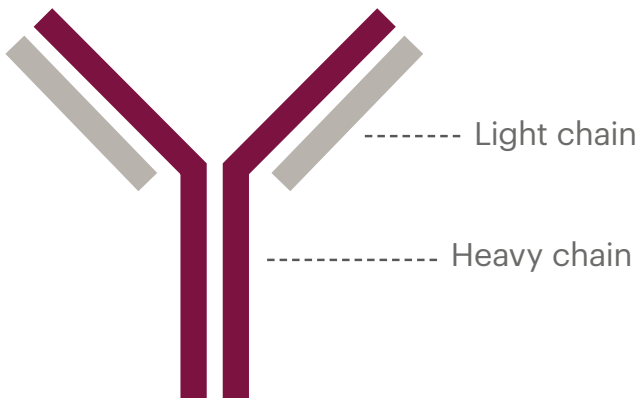
What is MGUS?

MGUS affects blood cells called plasma cells which are found in the bone marrow. Bone marrow is the spongy material inside some of our bones where most of our blood cells are made.

Normally, plasma cells make antibodies, Y-shaped proteins which help our bodies fight off infections like viruses and bacteria. If you have MGUS, some of your plasma cells make antibodies that don't work properly. These abnormal antibodies are called paraproteins or M-proteins.

Sometimes the plasma cells only make small pieces of an antibody called light chains.

Structure of an antibody



Paraproteins and light chains circulate in your bloodstream and may show up in a blood test. In MGUS, the levels are low and usually don't cause any health problems.

If you would like to find out more about paraproteins and light chains, go to [bloodcancer.org.uk/mgus](https://www.bloodcancer.org.uk/mgus) or call us on **0808 2080 888**.

How will having MGUS affect me?

In most cases, MGUS has no effect on how you feel physically. You are unlikely to have any symptoms and won't need treatment, but you will have regular check-ups to monitor the MGUS.

A few people with MGUS experience numbness or tingling in their hands and feet, or problems with their balance. This is a type of nerve damage that's sometimes caused by paraprotein in the blood. The medical name for this is peripheral neuropathy.

If you start having these symptoms or you notice them getting worse, let your doctor know. You may be referred to a neurologist, a doctor who specialises in conditions of the nervous system.

It's understandable to feel anxious if you get a diagnosis of MGUS. But it's important to know that MGUS is not blood cancer, doesn't need treating and shouldn't affect your daily life.

What's the connection between MGUS and blood cancer?

People with MGUS have a higher risk than normal of developing blood cancer, but the risk is still low. Your doctor may talk about your “risk of progression” – the chance of the MGUS changing into a type of blood cancer.

It is rare for MGUS to progress to blood cancer. Research suggests that each year about one in a hundred people (1%) with a diagnosis of MGUS go on to develop blood cancer.

Your personal level of risk depends on:

- the level and type of paraprotein in your blood
- whether there is an abnormal proportion of two types of light chain (called kappa and lambda) in your blood
- the number of abnormal plasma cells in your bone marrow – although most people with MGUS won't have a bone marrow test unless other tests show cause for concern (see page 9).

The medical professional who is monitoring the MGUS (your GP, specialist doctor or nurse) is the best person to tell you about your personal level of risk. But if you are worried, you can also contact our Support Service to talk things through.

What happens if MGUS progresses?

If MGUS progresses, it usually develops into a blood cancer called myeloma. There's no cure for myeloma yet, but it is treatable.

In a few cases, MGUS can develop into a type of lymphoma called Waldenström macroglobulinaemia (WM). WM is also a treatable blood cancer.

Remember that it is rare to develop either type of blood cancer.

If you would like to find out more about myeloma or WM, we have information at bloodcancer.org.uk/myeloma and bloodcancer.org.uk/wm

You can also order free booklets about these conditions from bloodcancer.org.uk/our-booklets or call us free on **0808 2080 888**.

How do I know it's MGUS not myeloma?

There are two main types of myeloma:

- **Smouldering myeloma** – This has no symptoms and doesn't need treatment but will be regularly monitored.
- **Active myeloma** – This will usually need treatment to control the myeloma and ease the symptoms.

Doctors will look at a range of things when deciding whether the diagnosis is MGUS, smouldering myeloma or active myeloma. The main ones are:

- the level of paraprotein in your blood
- the number of abnormal plasma cells in your bone marrow
- whether there are signs of damage in your body, in particular kidney or bone damage.

If you need to talk

If you want to talk about what your diagnosis means, how you're feeling or what to do next, contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk** and tell us that you've just been diagnosed with MGUS.

Or talk to people who've been where you are now on our online community forum:
bloodcancer.org.uk/our-forum

Are there any changes I should look out for?

Usually with MGUS you won't have any symptoms. But if you notice any changes in how you feel, tell your doctor. The main things to look out for are:

- pain in your back, ribs or hips for no apparent reason
- breathlessness
- extreme tiredness
- repeated infections
- generally feeling unwell or unable to do things you usually can.

If you have any of these symptoms, you may need more tests to find out whether it's caused by a change in the MGUS or something else.

Will I need treatment?

MGUS doesn't need treatment, but you will have regular check-ups. This is because of the small risk of MGUS developing into blood cancer.

If your test results stay the same over time, you may need check-ups less often or even stop needing them.

What are the tests to diagnose MGUS?

If a blood test shows you have paraprotein in your blood, it's likely that your doctor will discuss the test results with a specialist doctor (consultant). They might also send you to see the specialist.

You may have more tests on samples of your blood or wee (urine). You may have an X-ray, CT or MRI scan.

Some people will have a bone marrow biopsy – this involves taking a sample of bone marrow from the back of your pelvis (the ring of bones at the base of your spine). A doctor will take the sample using a needle, and you will have a local anaesthetic to numb the area. Some people find it painful, but others manage easily – everyone is different. Your hospital will tell you about the pain relief they can offer to make you more comfortable.

If you need a bone marrow biopsy, you'll have it as a day patient. You won't need to stay in hospital overnight.

The main aim of all these tests is to rule out myeloma, lymphoma or any other blood condition and find out more about the type of MGUS you have.

If you are worried about any tests or want more information, talk to your GP or hospital team, read our information at **[bloodcancer.org.uk/tests](https://www.bloodcancer.org.uk/tests)** or contact our Support Service on **0808 2080 888**.

How will the MGUS be monitored?

You may have blood tests every 3–6 months for the first year, followed by checks every 6–12 months after that. Your tests may happen less often if you have a very low risk of developing blood cancer (a very low risk of progression).

Your blood tests may be arranged by your GP, or in hospital by a specialist nurse or a haematologist – a doctor who specialises in blood conditions. You will also be monitored for any symptoms that could show a change in your condition. People who have a higher risk of developing blood cancer (a higher risk of progression) tend to be monitored by a hospital team.

What will happen at my check-ups?

At your check-ups, you'll have more blood tests and sometimes urine tests to see if there have been any changes since your last appointment. Your doctor or nurse will also ask you if there's been any change in how you feel.

If your results don't vary much and you don't have any symptoms, you may need check-ups less often or may not need them at all.

Can I see my blood test results?

You can ask for a printout of your blood test results. Make sure you ask your doctor to explain what the results mean.

Can I do anything to stop MGUS progressing?

The simple answer is no, there is no evidence that any changes in lifestyle will make a difference to whether MGUS progresses. The important thing is to go to your check-ups and tell your doctor if you notice any changes in your health.

Should I make any changes to my daily life?

You may find it helpful to follow general advice on healthy eating and exercise from the NHS. This can help with your emotional well-being as well as your overall physical health. Visit [nhs.uk/live-well](https://www.nhs.uk/live-well)

Because MGUS affects your antibodies, you may be more likely than the general population to get infections from bugs like bacteria and viruses. So it's important to follow standard hygiene and food safety advice. You should also make sure you have all the recommended vaccinations (jabs). Ask your GP if you're not sure which ones you should have.

We have information about avoiding infection at [bloodcancer.org.uk/managing-infection](https://www.bloodcancer.org.uk/managing-infection)

Am I at higher risk from covid-19?

Recent research suggests that having MGUS does not increase your risk of getting seriously ill from covid-19. So people with MGUS are not recommended to take extra precautions, unless they are in a high risk group for another reason.

What can I do if I'm worried?

You may feel anxious about your risk of developing blood cancer, even though the risk of progression is low. That's completely understandable.

Hopefully it's reassuring to know you will be monitored by your GP or a specialist. It means that if there are any signs of the MGUS progressing they will be picked up early. But for a lot of people, check-ups mean an anxious wait for test results before they can relax again.

Here are some ways to look after your mental health when you're being monitored for MGUS:

- Talk through your worries with the people you're close to. People are often surprised how helpful it is just to say your worries out loud, especially to someone they know is a good listener.
- You may find it easier to talk to someone you don't know. Our Support Service is here on **0808 2080 888** or **support@bloodcancer.org.uk** if you'd like to talk anything through or just tell someone how you're feeling.

- Getting answers to your questions can help. Many people find it useful to write down their questions before an appointment, so they remember to ask their GP or hospital team everything they want to know. You can also ask if it's OK to bring someone along to your appointments.
- Talking to other people in the same situation can be a relief, as they'll understand how you're feeling. You'll find a community of people with MGUS and other conditions at **bloodcancer.org.uk/our-forum**

Useful publications

Printed resources

- **Myeloma: Your guide to diagnosis, treatment and living well with myeloma**
- **Waldenström macroglobulinaemia (WM)**

Order free copies at bloodcancer.org.uk/our-booklets or call us free on **0808 2080 888**.

Online resources

- more information about mgus:
bloodcancer.org.uk/mgus
- tests you may have:
bloodcancer.org.uk/tests
- managing your risk of infection:
bloodcancer.org.uk/managing-infection
- information about myeloma:
bloodcancer.org.uk/myeloma
- information on Waldenström macroglobulinaemia (WM):
bloodcancer.org.uk/wm
- current blood cancer research:
bloodcancer.org.uk/researching
- ways to get involved with Blood Cancer UK:
bloodcancer.org.uk/involved

Because we face it together

If you've been told you have MGUS, we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.



bloodcancer.org.uk



0808 2080 888 (calls are free and confidential)



support@bloodcancer.org.uk



bloodcancer.org.uk/our-forum



Blood Cancer UK



[@bloodcancer_uk](https://www.instagram.com/bloodcancer_uk)



[@bloodcancer_uk](https://twitter.com/bloodcancer_uk)



Blood Cancer UK

Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Dr Simon Stern and Dr Kamaraj Karunanithi for checking the medical content, and to all the people living with MGUS who kindly gave us their feedback.

A list of references used in this booklet is available on request. Please email information@bloodcancer.org.uk

Disclaimer

We make every effort to ensure that the information in this booklet is accurate, but you should always seek advice from your doctor if you have any concerns or questions about your health. As far as applicable by law, Blood Cancer UK cannot accept responsibility for any loss or damage resulting from any inaccuracy in this information, or in external information that we link to.

By law, this disclaimer cannot limit or exclude our liability for death or personal injury resulting from negligence, or any other liabilities that cannot be excluded under applicable law.

Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at bloodcancer.org.uk

Or call us free on **0808 2080 888**

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The information in this booklet was correct at the time it was printed (April 2023). Date of next full review: April 2026.

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Blood Cancer UK is a trading name of Bloodwise,
5-11 Theobalds Road, London WC1X 8SH.

A company limited by guarantee 738089 (registered in England and Wales)
Registered charity 216032 (England and Wales) SCO37529 (Scotland)

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