

Monoclonal gammopathy of undetermined significance (MGUS)

MGUS is a blood condition where plasma cells (blood cells involved in your immune system) behave abnormally. MGUS itself is generally a harmless blood condition, however a small number of people with MGUS go on to develop blood cancer.



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How we can help

We're a community dedicated to beating blood cancer by funding research and supporting those affected. We offer free and confidential support by phone or email, free information about blood cancer, and an online forum where you can talk to others affected by blood cancer.



bloodcancer.org.uk

forum.bloodcancer.org.uk



0808 2080 888

(Mon, Tue, Thu, Fri: 10am–4pm, Wed: 10am–1pm)



support@bloodcancer.org.uk

What is MGUS?

Plasma cells are a type of white blood cell that help your body fight infection. We all have small numbers of plasma cells in our bone marrow.

Plasma cells produce antibodies (also known as gamma globulins or immunoglobulins). These are made of proteins and help fight infection. If there's an infection in your blood, the plasma cells in your bone marrow should multiply to form a group of cells which produce large numbers of antibodies to fight the infection.

If you have MGUS, the plasma cells in your bone marrow form a group of identical (clonal) plasma cells, even though there isn't an infection obviously present. These cells will all produce an identical antibody which is called a paraprotein, monoclonal protein or M-protein.

The M in MGUS stands for ‘monoclonal’ (meaning ‘from one clone’) because the plasma cells are all clones of one cell and create one type of antibody.

MGUS itself is harmless, and most people with it remain well. However, research suggests that a small number of people with MGUS (1% every year) will go on to develop a type of blood cancer called myeloma. And sometimes, people with MGUS develop a rare form of lymphoma called Waldenström macroglobulinaemia (WM).

If you've just found out that you or someone you know has MGUS, it's important to remember that most people with MGUS (we think about 80%) never go on to develop blood cancer.

What causes MGUS?

We don't know what causes MGUS but we do know that you can't catch it from someone else (it's not contagious).

There are certain factors that affect your risk of developing MGUS:

- **Age.** MGUS becomes more common as people get older and is often diagnosed in people over 70 years old. Around 5–10% of people over 70 have MGUS and 3% of over 50s have MGUS.
- **Sex.** MGUS is more common in men than women.

- **Ethnicity.** Black people from an African background are more likely to develop MGUS than white people from a European background. We're not yet sure about the differences in people from other ethnic backgrounds.
- **Immune conditions.** MGUS is more common in people with conditions such as rheumatoid arthritis that affect their immune system. Your immune system is the network of cells, tissues and organs which protect your body against infection.
- **Family history.** MGUS can't be passed down from parent to child (inherited), although there's some evidence that having a family member with MGUS means you're more likely to develop it yourself. We don't know if this is because of a genetic fault or if it's because members of the same family are more likely to have the same type of lifestyle.

What are the symptoms?

People with MGUS usually have no or few symptoms. Some people have numbness or tingling in their hands and feet, or problems with their balance due to damage to the nerves (peripheral neuropathy) caused by the paraprotein in the blood.

If you experience any of these symptoms or they get worse, you may be referred to a neurologist (a doctor who specialises in conditions of the nervous system).

How is MGUS diagnosed?

Most people are diagnosed with MGUS when they're having blood tests as part of a routine check-up or when their doctors are screening or testing them for other medical problems.

The first thing that's usually noticed is a high level of protein in your blood.

What tests will I need?

If your doctor thinks you might have MGUS, you'll usually have blood and urine tests. You may also have some more tests to check for any symptoms of myeloma or lymphoma. These tests may include x-rays, scans, and sometimes, a bone marrow test.

Blood tests

To get an initial diagnosis, you'll have some blood tests to:

- measure the type and amount of paraprotein produced by your plasma cells
- look for anaemia and measure numbers of normal blood cells by doing a full blood count (FBC)
- check your kidney and liver function
- check your calcium levels.

Urine tests

You may also be asked to give samples of your urine, which will be checked for paraproteins.

Bone marrow test

If the paraprotein level is high in your blood, your blood test results are abnormal, or you have some symptoms, your doctor may suggest you have a bone marrow test, also known as a biopsy. This is normally done as an outpatient.

X-rays and scans

In some cases, you may have a full body X-ray, CT or MRI scan to check for any bone damage.

After these tests, if your doctor has ruled out myeloma and lymphoma, and the only problem found is a raised level of paraprotein in your blood, then you'll be told you have MGUS.

Find more information about blood tests and bone marrow tests at **bloodcancer.org.uk/tests**

Will I need treatment?

MGUS doesn't need treatment and it doesn't usually cause any symptoms.

However, because of the risk of MGUS developing into myeloma, you'll be monitored regularly by your healthcare team.

You should always check with your doctor if you experience any new symptoms, including:

- constant pain, which may be in the bones, in one area (back, ribs, hip or pelvis) for no apparent reason
- breathlessness
- extreme tiredness (fatigue)
- recurring infections.

Your appointments

You'll have follow-up appointments with your GP or at a haematology (blood disorder) clinic at the hospital.

You can discuss with your doctor where you'd prefer to have these appointments. This will also depend on your personal circumstances and the level of paraprotein in your blood.

Once a diagnosis of MGUS is confirmed, and as long as you remain well, your follow-up appointments will happen every six months. Your doctor will check for any new symptoms, such as unexplained bone pain, or feeling tired (which can be caused by anaemia – a low level of red blood cells).

If everything has remained stable for some time, your tests may happen less often.

Your outlook

Most people with MGUS will never develop any symptoms. However, each year about 1% of people with MGUS will develop myeloma or a related condition.

For more information about myeloma, visit **bloodcancer.org.uk**. You can also order or download our booklet on **Myeloma**.

Living with MGUS

Although most people with MGUS will never experience any symptoms and remain well, being told that you have MGUS can be worrying. For example, you might feel anxious about your diagnosis and around the time of your check-ups.

It's important that you look after yourself emotionally by talking to others. Our Support Services Team is here to help on **0808 2080 888**, whether you have MGUS yourself, or are concerned about a loved one.

Looking after yourself physically by keeping active and eating a varied and balanced diet can help you feel better too.

Connect with other people with MGUS on our online community forum at **forum.bloodcancer.org.uk**

You may also find our web pages on living well helpful. They've been written for people with blood cancer, but contain lots of useful tips: **bloodcancer.org.uk/living-well**

Notes:

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About this fact sheet

We have produced this fact sheet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Consultant Haematologists Dr Andrew Chantry and Dr Stella Bowcock for their support checking the content of this fact sheet.

Our fact sheets contain general information. Always listen to the advice of your specialist about your individual condition because every person is different.

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

Disclaimer

We make every effort to make sure that the information in this fact sheet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

The information in this fact sheet is correct at the time it was published (July 2017).

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Because we face it together

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