

Your patient diary

A stylized orange pencil icon pointing downwards and to the left, positioned at the end of a horizontal line that underlines the title.

For patients with Monoclonal Gammopathy
of Undetermined Significance (MGUS)

This diary is for patients with Monoclonal Gammopathy of Undetermined Significance (MGUS). It explains what MGUS is, why and how you will be monitored, and has space for you to keep a record of your test results.



You may also like to read the **MGUS Infosheet** from Myeloma UK for more information about the condition

My details

Name

NHS number (England & Wales)

CHI number (Scotland)

Health and Care number (N. Ireland)

Address

I was diagnosed with Monoclonal Gammopathy of Undetermined Significance (MGUS) on

My healthcare team's details

I am being monitored by my...

GP

Nurse

Haematologist

Other:

Name

Phone number

Monoclonal gammopathy of undetermined significance (MGUS)

What is MGUS?

MGUS is a condition where an abnormal protein (called a paraprotein) is produced by the body and found in the blood and/or urine. The cause is unknown and people with MGUS rarely require treatment.

MGUS is not cancer.



For more information see the **MGUS Infosheet** from Myeloma UK

Why am I being monitored?

Many patients with MGUS remain well and never develop any problems related to it. However, a very small number of people with MGUS go on to develop another, more serious condition. For example, over a 10-year period, 10% of people (1 in 10 people) with MGUS will develop myeloma (a blood cancer).

For this reason, it is important to have regular blood tests to check for any change in your condition. Regular checks will make sure that if you need treatment, you can have it as soon as it is necessary.

How will I be monitored?

You will be monitored by someone in your healthcare team – this may be your GP, a specialist nurse or haematologist (a doctor specialising in blood conditions and cancers). No matter who is monitoring you, you will have the same tests done. You might have a phone appointment or visit the GP surgery/hospital.

Although all patients will have the same tests done, how often they are carried out can vary according to the risk of progression. Patients with lower risk will be monitored less frequently than those with higher risk. This risk assessment is carried out at diagnosis.

Blood tests

Usually, you will have blood tests every three to six months to pick up any changes in your condition. Over time, these tests may be reduced to once a year. If you are a low risk patient, you may start with tests once a year. Your healthcare team will monitor the results.

You will need to make regular appointments to have these blood tests.

If you move house remember to register with a GP as soon as possible and check with your new GP about having your tests done.

Symptom checks

Your healthcare team will also monitor your general health to see if you develop any symptoms that could indicate a change in your condition. It is important that you report any of the following problems as soon as possible:



Pain, particularly in your back or ribs



Fatigue



Recurrent infections



A bone fracture or crushed backbone (vertebra) after minor injury

If you experience any of these problems, it is important that you tell your healthcare team as soon as possible (within 2 weeks). You should not wait until your next appointment to tell them.

Understanding blood tests

You will have three types of blood tests to monitor your MGUS.

1. Full blood count (FBC)

A full blood count is a test that measures the numbers of cells in your blood. This can be used to help your healthcare team check your general health and as an early test for blood cancers. The cells they measure are:

- **Red blood cells (RBC)** – contain haemoglobin (Hb), which carries oxygen to all the cells in your body. The haemoglobin levels in your body show how many red blood cells you have. A low Hb level will cause you to be anaemic which can make you feel tired and breathless
- **White blood cells (WBC)** – fight infections. There are several different types of white cells, including neutrophils and lymphocytes. Low levels can make you at greater risk of infection
- **Platelets** – help clot the blood. If you have low platelets, you may have abnormal bleeding, such as bleeding gums, nosebleeds and bruising

2. Urea and electrolytes (U&Es)

This test will show how well your kidneys are working. It measures the level of certain chemicals and minerals in your blood – urea, creatinine and calcium.

3. Paraprotein level

Paraproteins are found in the blood and/or urine of people diagnosed with MGUS. Your blood will be tested to measure the level of paraprotein in it.

You will also have a test to measure the level of light chains in your blood (light chains normally make up part of the paraprotein but can also exist separately).

If your healthcare team does not have access to this test (called a serum free light chain test), your urine will be tested for light chains instead. This is known as a Bence Jones test.

How will I know if my MGUS is progressing?

The key things your healthcare team will be looking out for in your blood test results are:

- Anaemia
- Reduced kidney function
- High calcium levels
- Raised paraprotein levels

They will look at trends in your results, rather than individual readings, as there can be fluctuations that do not mean your MGUS is progressing.

You should talk to your healthcare team if you are worried about any changes in your test results.

The normal ranges for these tests results are shown in the table opposite.

Managing changes to your MGUS

It can be worrying to see changes in your test results, but your healthcare team will be monitoring you and will pick up on any changes.

If your test results have changed or you have any of the symptoms listed on page 4, talk to your healthcare team.

If you are being monitored by your GP, they may refer you to a haematologist if there are any concerns, for example, if the paraprotein level has increased on several occasions. Your GP will make this referral by email and you should receive an appointment within 14 days.

Test		Levels found in a healthy person
Full Blood Count (FBC)	Haemoglobin (Hb)	135–180 g/L (men) 115–165 g/L (women)
	White Cells (WBC)	4.0–11.0 x10 ⁹ /L
	Platelets	150–400 x10 ⁹ /L
Urea & Electrolytes (U&Es)	Urea	2.5–6.7 mmol/L
	Creatinine	70–150 mmol/L
	Calcium	2.10–2.65 mmol/L
Paraproteins	Paraprotein Level	0
	Serum Free Light Chain Level	0

Table 1. Normal ranges for test results.

Recording your test results

The charts on the following pages are for you to record your test results.

Remember to take this booklet with you each time you have your tests done.

It is very important that you make regular appointments for your blood tests and monitoring. If you have any of the symptoms listed on page 4, speak to your healthcare team as soon as possible.

Key points to remember

- MGUS is not a cancer
- People with MGUS are monitored regularly because, for a very small number of people, it can develop into a more serious condition
- You will have blood tests to monitor your MGUS
- You need to make regular appointments with your GP, nurse or haematologist
- You should report any of the physical problems listed on page 4 to your healthcare team as soon as possible
- If you move house remember to register with a GP as soon as possible and check with your new GP about having your tests done



Further help and support

Living with MGUS can be difficult at times and you may feel anxious or worried. If you want more information or would like some support, get in touch with Myeloma UK by calling the Myeloma UK Infoline on **0800 980 3332** or by emailing **AskTheNurse@myeloma.org.uk**

Date						
Haemoglobin (Hb)						
FBC White Cells (WBC)						
Platelets						
Urea						
U&Es Creatine						
Calcium						
Paraproteins Paraprotein level						
Serum Free Light Chain Level						

Notes

 You can download extra results table pages from the Myeloma UK website at myeloma.org.uk/mgus-diary

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For patients with MGUS



We're here for everything a diagnosis brings

Get in touch to find out more about how we can support you

Call the Myeloma UK Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**

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