Your patient diary

For patients with Monoclonal Gammopathy of Undetermined Significance (MGUS)

This diary is for patients with Monoclonal Gammopathy of Undetermined Significance (MGUS). It has been designed to help you stay informed and to help keep track of information related to your MGUS. There is space at the back of the diary to record your blood results and any questions you have for your healthcare team. Remember to take it with you to each of your appointments.

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

My details

Name

Address

Telephone (Home)

Telephone (Work)

Mobile

Email address

NHS number (if known)

Date of Monoclonal Gammopathy of Undetermined Significance (MGUS) diagnosis

My healthcare team's details

I am being monitored by my...

☐ GP ☐ Nurse ☐ Haematologist

Name

Location

Telephone

Monoclonal Gammopathy of Undetermined Significance (MGUS)

What is MGUS?

MGUS is a condition where a type of white blood cell (plasma cell), produces an abnormal protein. This abnormal protein is called a paraprotein and has no useful function. Generally MGUS does not cause any symptoms and it rarely needs treatment.

MGUS is **not a cancer**.

Some people have a form of MGUS where the paraprotein or light chain (part of the paraprotein) is causing specific symptoms and complications. This is called Monoclonal Gammopathy of Clinical Significance (MGCS).

For more information see the **MGUS Infosheet** and the **MGCS Infosheet** from Myeloma UK.

Why am I being monitored?

Although MGUS is not a cancer, people with MGUS have a slightly higher risk of developing blood cancer. Each year, around 1 in 100 people with MGUS develop a related blood cancer, such as myeloma or lymphoma. However, most people with MGUS never develop a related cancer.

Regular monitoring ensures that any changes to your MGUS are detected as early as possible.

How will I be monitored?

Regular symptom checks and blood tests are used to monitor your MGUS. A GP, specialist nurse or haematologist (specialist doctor for blood conditions) can arrange these tests. Every patient will

receive the same tests, but how often you have them may vary from person to person. If you have MGCS you may have additional tests to monitor the complications the MGCS is causing.

Symptom checks

Your healthcare team will monitor you for any symptoms that could suggest a change in your MGUS. Contact your healthcare team as soon as possible and do not wait for your next appointment if you develop any of the following symptoms:

Pain, particularly in your back or ribs

Fatigue

Frequent infections, or infections that do not go away easily

Unexpected bone breaks, or breaks after minor injury

Numbness or tingling in the hands, feet or legs

Blood tests

You may have blood tests every 3 to 6 months when first diagnosed, or if you are considered at higher risk of developing a cancer. If your test results have remained stable for some time, or you are considered low risk for developing a cancer, you may have these tests once a year.

You may need to make regular appointments yourself to have these blood tests. Speak to your healthcare team to about how your blood test appointments should be made.

Understanding blood tests

You will have 3 types of blood tests to monitor your MGUS. The normal ranges for these blood tests are shown on page 6.

1. Full blood count (FBC)

Different types of blood cells have different functions in the body. A full blood count measures the number of these different cells in your blood. The types of cells measured are:

- **Red blood cells (RBC)** – carry oxygen around the body using a chemical called haemoglobin. Low haemoglobin levels indicate anaemia, which may make you feel tired and breathless, and make your skin look paler than usual
- **White blood cells (WBC)** – fight infections. Low white blood cell levels can increase your risk of infection
- **Platelets** – help blood to clot. Low platelet levels may increase your risk of bleeding including bleeding gums and nosebleeds

2. Blood chemistry

Kidneys filter out waste chemicals from the blood. A blood chemistry test measures these different chemicals including urea, calcium and creatinine. These measurements are used to calculate your estimated glomerular filtration rate (eGFR), which shows how well your kidneys are working. A low eGFR suggests the kidneys are not working normally.

3. Paraprotein level

Paraprotein is the abnormal protein found in the blood and urine of people with MGUS.

Light chains form part of a paraprotein and can be measured in the blood. They can also be measured in the urine using a Bence Jones test.

Blood tests and normal ranges

Blood test	Measurement	Normal range*	Notes
Proteins	Paraprotein	0 g/L	Abnormal protein found in certain conditions, including MGUS and myeloma
	Serum free Kappa (κ)/ Lambda (λ) ratio	0.26–1.65	Part of an immunoglobulin (antibody). Levels are often raised in myeloma
Full blood count	Haemoglobin (Hb) (men)	135–180 g/L	A low haemoglobin (Hb) causes anaemia and fatigue
	Haemoglobin (Hb) (women)	115–160 g/L	
	White blood cells (WBC)	4.0–11.0 $\times 10^9$/L	A low white blood cell count increases your risk of infection
	Platelets (Pl)	150–440 $\times 10^9$/L	A low platelet count increases your risk of bruising and bleeding
Blood chemistry	Urea	2.5–6.7 mmol/L	Often raised when kidneys are not working properly
	Estimated glomerular filtration rate (eGFR)	90 ml/min or above	Often lowered when kidneys are not working properly
	Calcium	2.1–2.65 mmol/L	Raised by myeloma bone disease

***The normal ranges listed are averages.** Exact ranges can vary between hospital laboratories and this table is for guidance only. Speak to your healthcare team if you need help understanding your blood results. They can interpret your results, specific to you.

Explanation of units

g/L – number of grams there are in a litre of blood

mg/L – number of thousandths of a gram in a litre of blood

$\times 10^9$/L – number of billion cells there are in a litre of blood

mole – a standard measurement for the amount of any chemical

mmol/L – number of thousandths of a mole in a litre of blood

Please note that doctors do not use a litre of blood to make these measurements; they just take a small sample (a few millilitres, or 2 to 3 teaspoons) and then multiply the results.

How will I know if my MGUS is changing?

A combination of your symptoms and blood tests will be used to determine if your MGUS is changing. Your blood tests will be checked for:

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

Your healthcare team will look at trends in your results rather than a one-off reading to determine any changes to your MGUS. Small fluctuations in results are common. Looking at test results over a longer time will give a more accurate picture of your MGUS.

Your healthcare team can help to explain your specific results and answer any questions you concerns you have.

Managing changes to your MGUS

Experiencing a change in your symptoms or being told there are changes in your blood tests can be a worrying and anxious time. You may feel reassured to know that regular monitoring means that changes are usually picked up as early as possible.

If you are being monitored by your GP or nurse, you will be referred to a haematologist for further tests.

Our Myeloma UK Information Specialists are available Monday to Friday 9am–5pm to provide emotional support and practical advice to anyone living with MGUS. Call or email:

0800 980 3332 (UK) or **1800 937 773** (Ireland)

AskTheNurse@myeloma.org.uk

Key points to remember

- MGUS is not a cancer
- People with MGUS have regular monitoring because for a small number of people (1 in 100 each year), MGUS may change into a related blood cancer, such as myeloma or lymphoma
- A combination of regular blood tests and symptom checks are used to monitor your MGUS
- You need to make regular appointments with your GP, nurse or haematologist
- Report any symptoms such as frequent infections, fatigue, pain in the back or ribs, unexplained bone fractures and numbness or tingling of the hands, feet or legs to your healthcare team as soon as possible. Do not wait until your next appointment

Further help and support

If you have any questions about MGUS or you need support, contact our friendly and experienced Myeloma UK Information Specialists by calling or emailing:

0800 980 3332 (UK) or **1800 937 773** (Ireland)

AskTheNurse@myeloma.org.uk

You can also read our **MGUS infosheet** for more information.

Recording your test results

The following pages are designed to help you keep track of your MGUS. It can help you stay informed and offers space to write any important information related to your MGUS.

If you have any questions or concerns about your blood results, ask your healthcare team to explain them. You can also write down your questions in the 'Questions and notes' section to ask at your next appointment. Be reassured that it is common to have concerns and questions.

Keep your diary readily available and record questions or symptom changes as soon as you can. Remember to take it with you every time you have an appointment for your MGUS.

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

Date				
Paraprotein level				
Light chains	Ratio:	Ratio:	Ratio:	Ratio:
Full blood count	Hb:	Hb:	Hb:	Hb:
	WBC:	WBC:	WBC:	WBC:
	Pl:	Pl:	Pl:	Pl:
Blood chemistry	Urea:	Urea:	Urea:	Urea:
	eGFR:	eGFR:	eGFR:	eGFR:
	Calcium:	Calcium:	Calcium:	Calcium:
Notes				

Date				
Paraprotein level				
Light chains	Ratio:	Ratio:	Ratio:	Ratio:
Full blood count	Hb:	Hb:	Hb:	Hb:
	WBC:	WBC:	WBC:	WBC:
	PI:	PI:	PI:	PI:
Blood chemistry	Urea:	Urea:	Urea:	Urea:
	eGFR:	eGFR:	eGFR:	eGFR:
	Calcium:	Calcium:	Calcium:	Calcium:
Notes				

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Paraprotein level				
Light chains	Ratio:	Ratio:	Ratio:	Ratio:
Full blood count	Hb:	Hb:	Hb:	Hb:
	WBC:	WBC:	WBC:	WBC:
	Pl:	Pl:	Pl:	Pl:
Blood chemistry	Urea:	Urea:	Urea:	Urea:
	eGFR:	eGFR:	eGFR:	eGFR:
	Calcium:	Calcium:	Calcium:	Calcium:
Notes				

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Light chains	Ratio:	Ratio:	Ratio:	Ratio:
Full blood count	Hb:	Hb:	Hb:	Hb:
	WBC:	WBC:	WBC:	WBC:
	PI:	PI:	PI:	PI:
Blood chemistry	Urea:	Urea:	Urea:	Urea:
	eGFR:	eGFR:	eGFR:	eGFR:
	Calcium:	Calcium:	Calcium:	Calcium:
Notes				

Questions and notes

Your patient diary:
For patients with MGUS

MyelomaUK

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

Trusted Information Creator
Patient Information Forum

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