IgM MGUS (Monoclonal Gammopathy of Uncertain Significance) – Patient information

Cancer Services and Clinical Haematology
Information for Patients

Produced: Dec 2023
Review: Dec 2026
Leaflet number: 2015
Version: 1

What is an IgM MGUS?

Your doctor may have told you that you have 'MGUS' which stands for monoclonal gammopathy of unknown significance. It is not a cancer but is a condition where the body makes an abnormal antibody, called a 'monoclonal (abbreviated as M)' protein or paraprotein.

There are many types of MGUS. And they are named according to the type of the backbone the paraprotein has:

- IgM MGUS
- Non-IgM MGUS – i.e. IgG, IgA, IgD or IgE
- Light chain MGUS – where there are no heavy chain backbone at all, only smaller so called lightchains (fragments of antibodies)

People with MGUS have a relatively small risk of developing blood cancers.

The IgM MGUS can progress into low-grade lymphomas, and other MGUS's can develop into Myeloma. The chances of progression to a form of blood cancer are low. The risk of progressing among patients with IgM MGUS is around 2% per year in the first 10 years after diagnosis and 1% per year thereafter. Despite the small chances, it is reasonable to monitor patients to detect the few who will progress.

What does monitoring consist of?

Monitoring consists of simple blood tests, often repeated once a year.

These should include:

- Quantification of the M protein on serum electrophoresis and immunoglobulin levels,
- Full blood count,
- Renal and liver function,
- Bone profile,

Occasionally other blood tests might be required.

A clinician will review these blood results. This might be in the form of a telephone or in-person consultation with a Clinical Nurse Specialist or a Consultant Haemato-oncologist. Or as an alternative, if your protein levels and symptoms are stable, we might offer to en-role you onto our Dawn Monitoring programme. This is where we provide you with the relevant blood test request forms and you have these performed locally to your home. You do not need to have a consultation, either on the phone or in person. We review your bloods and write a summary to you to inform you that they are stable. If there is any concern or change we will contact you to arrange a consultation.

If, while on this monitoring programme, you develop any of the below symptoms we would ask you to contact your GP for assessment as often symptoms are very varied and might be indicative of other concerns and not linked to your IgM MGUS. This should be your normal first port of call for any changes in your health status.

Dawn Monitoring Contact details

DAWN clinic coordinator, who can help with lost blood forms etc.

Monday to Friday 9am to 5pm

Tel: **07929 793688**

What happens if my paraprotein levels are rising?

Over time, your paraprotein levels may fluctuate, which in itself it is not of any concern. If there is a continuous increase or signs, symptoms which may be caused by developing an underlying medical condition, for example, rapid weight loss or feeling breathless and fatigued from a new anaemia, this may trigger further investigations.

If your paraprotein increases and you have symptoms, you may be asked to have more frequent monitoring or to undergo a CT scan or bone marrow test. If you need this we will give you more information regarding this.

Will I have any symptoms with an IgM MGUS?

Generally, having an IgM MGUS will not cause any symptoms. If you have unexplained symptoms they are likely to need further investigations, as you may be developing an underlying low-grade lymphoma or you may have a form of IgM M-protein which has a clinical significance (as opposed to unknown significance). This has been termed monoclonal gammopathy of clinical significance (MGCS).

Other conditions which you might experience:

- IgM related neuropathy, causing numbness in your hands or feet, or balance problems;
- an IgM related autoimmune condition such as cold agglutin disease
- an IgM gammopathy of renal (affecting the kidney) significance.

- Amyloidosis a separate condition where the protein is deposited in organs such as your heart, kidney and nerves.

Further specialised tests and examinations will help to determine these types of conditions. These conditions may have additional signs and symptoms such as enlarged organs or abnormal hormone levels or skin abnormalities. It is important to let your clinician know if you have any symptoms that you are concerned about.

Symptoms which may be of concern to report:

If your blood tests remain stable, it is very unlikely that you would develop any symptoms or problems related to your MGUS. If you have any new symptoms, such as those listed below, please contact your GP.

- extreme tiredness
- feeling short of breath
- recurrent infections
- bone pain affecting your back, ribs, arms or legs
- nausea and/or vomiting
- confusion
- unexplained weight loss
- night sweats- drenching in nature
- new lumps or swelling, particularly in your neck, armpit or groin
- New headaches
- numbness of the hands or feet
- abnormal bleeding

A very small number of people with MGUS will develop problems with vision. Please see an optician if you have any vision changes. They can then refer you to the ophthalmology (eye) department for further tests if they are worried that the changes are related to your MGUS.

What type of low-grade lymphoma might an IgM MGUS this develop into?

A very small number of patients with an IgM MGUS can go on to develop a low-grade (slow growing) lymphoma, such as Waldenstrom's Lymphoma or a Marginal Zone Lymphoma. Less likely, a chronic lymphocytic leukaemia (CLL), or a very rare type of Myeloma. If diagnosed with a low-grade Lymphoma, you may not need treatment, but you will require monitoring to see if treatment is required in the future. If the low-grade Lymphoma is causing symptoms, a course of treatment will be recommended. Treatment will generally consist of a combination of intravenous anti-body treatment and chemotherapy given on our day unit as a day case or sometimes it can be in tablet form.

The Rory Morrison WMUK Registry

Working with centres across the UK, The Rory Morrison WMUK Registry gathers data from patients with IgM MGUS and related disorders. At Leicester we do not routinely share data with this register. So you can contact WMUK directly if you would like to participate, or obtain some further information.

How can I find out more information?

You can find out more from:

Lymphoma Action at lymphoma-action.org.uk

Waldenstrom's UK at wmuk.org.uk

UHL MGUS (Monoclonal Gammopathy of Uncertain Significance): How we follow you up-DAWN Monitoring patient information leaflet.

Dawn Monitoring Contact details

DAWN clinic coordinator, who can help with lost blood forms etc.

Monday to Friday 9am to 5pm

Tel: **07929 79368**

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.

To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

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If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net

We are a research hospital and you may be asked to take part in research

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