

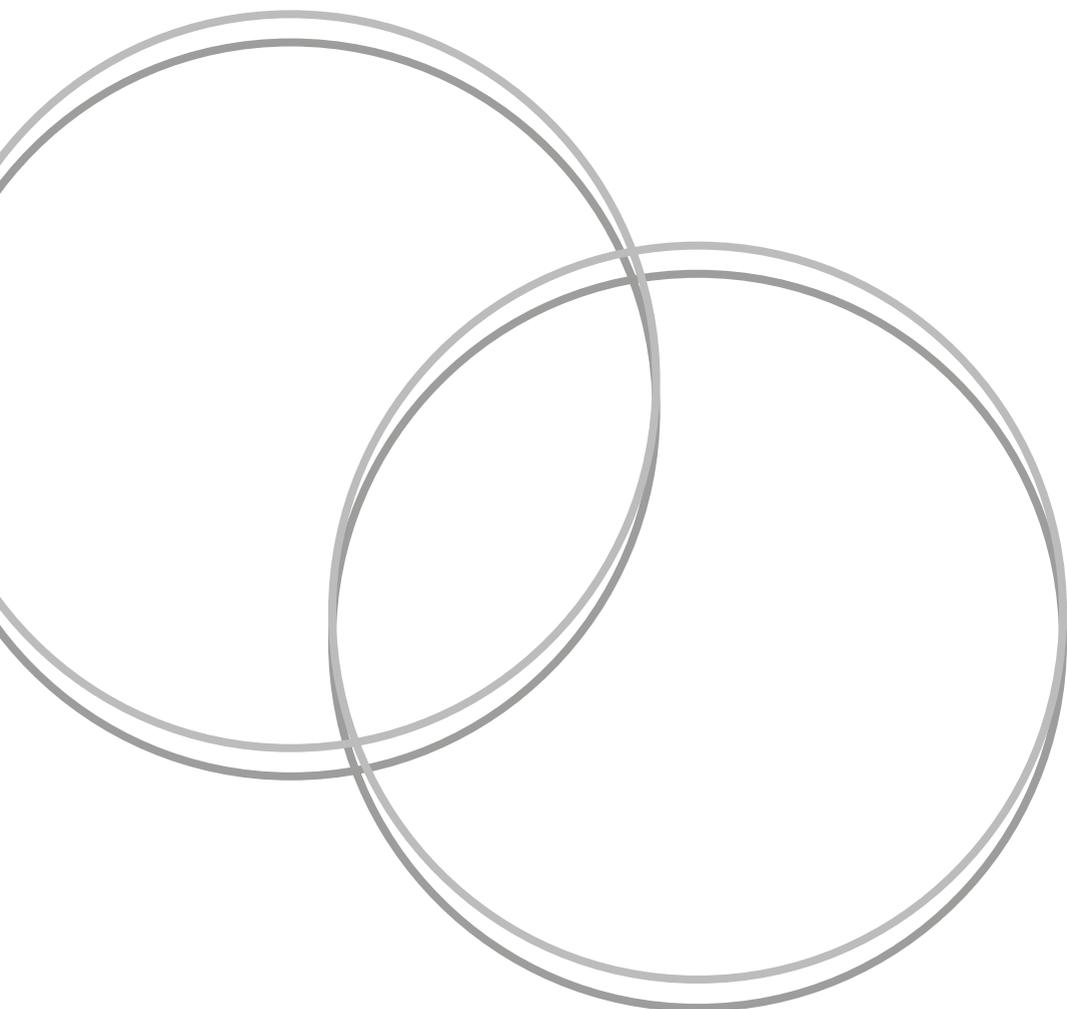


Oxford University Hospitals  
NHS Foundation Trust

# MGUS

## When to Contact Your Nurse Specialist

Information for patients





## Introduction

This information is for people with a disorder of the blood called 'monoclonal gammopathy of unknown significance' (MGUS).

MGUS means that your blood cells are making an abnormal protein called a paraprotein. It is a non-cancerous condition. It is usually found when you have a routine blood test for another reason.

This leaflet is for people with MGUS who are being monitored by our Haematology clinic.

**You will find more information about MGUS on the websites listed at the end of this document.**

## Monitoring your MGUS

You have been referred to our clinic so that we can monitor your condition with regular blood tests. You will have telephone appointments with a specialist nurse. We will ask you how you are feeling and will discuss any changes in your health.

Most people with MGUS will have no physical symptoms. However, a small proportion of people will develop symptoms that might suggest a change in their condition. This leaflet explains what these symptoms are and what you should do if you notice them.

## **Symptoms to look out for**

MGUS may affect organs such as your bone marrow and kidneys. The following symptoms might indicate a need for further investigation.

**Please contact your nurse specialist if you have any of these symptoms.**

### **Pain**

You might experience pain that comes on suddenly and gets worse. It is normally bone pain, usually in the back and the ribs, but it can be in other places. If you already have pain because of another condition, then this pain might become worse for no obvious reason. This pain can make you feel that you need to take painkillers or increase the amount of painkillers you normally take.

### **Drowsiness, fatigue or lethargy**

You might have fatigue or extreme tiredness that is getting worse and making it difficult to do your normal daily activities. This might include finding it hard to concentrate. You might feel this way even when you are getting enough sleep.

### **Confusion**

You may be feeling confused a lot of the time. People close to you might notice this and be worried about it. If you have memory problems they might get worse.

### **Urinary symptoms**

You might find that you are not passing as much urine as normal or that your urine is dark in colour, even though you are drinking the same amount as usual. Ideally urine should be straw coloured. You might notice that your urine is frothy or bubbly.

### **Drenching night sweats**

You might sweat a lot during your sleep. This means sweating so much that you have to change your night clothes and bedding.

## **Unexplained weight loss**

You might lose weight without trying and without changing your diet or exercise routine.

## **Feeling breathless on exertion**

You might start to feel unusually short of breath after exerting yourself. This might happen at the same time that you become increasingly tired or fatigued.

## **Infection**

You might start having a lot of infections such as chest infections or urinary tract infections that keep coming back in a short space of time.

## **Other possible symptoms linked to high blood calcium levels**

Other symptoms of high calcium include thirst, nausea, vomiting, and constipation.

## **Keeping records**

You will have regular blood tests to check on the levels of abnormal cells in your blood. In between blood tests, you should pay attention to how you are feeling. Notice what feels abnormal for you.

You may wish to keep a record of anything you notice that is out of the ordinary. Make a note of when it happened and how long it lasted. If you are worried, contact your specialist nurse using the details on page 6.

## **When to contact your GP**

Contact your GP if you have new symptoms that are not listed here.

## **When to contact the specialist nurse**

Contact the specialist nurse if you have any of the symptoms above, or if you have any questions or concerns about MGUS.

## Contact details

### Myeloma Senior Specialist Nurse

Telephone: 01865 227 430  
(Answerphone in use out of hours).

Email: MyelomaCNS@ouh.nhs.uk

Office hours: Monday and Thursday 8am to 4pm  
Wednesday and Friday 8am to 6pm

## For more information about MGUS

Website: [www.macmillan.org.uk/cancer-information-and-support/worried-about-cancer/pre-cancerous-and-genetic-conditions/mgus](http://www.macmillan.org.uk/cancer-information-and-support/worried-about-cancer/pre-cancerous-and-genetic-conditions/mgus)

Website: [www.myeloma.org.uk/understanding-myeloma/related-conditions/mgus/](http://www.myeloma.org.uk/understanding-myeloma/related-conditions/mgus/)



## Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Lisa Ferguson and Dr Jaimal Kothari, with input from members of the Oxford Blood Group.

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Oxford University Hospitals NHS Foundation Trust

[www.ouh.nhs.uk/information](http://www.ouh.nhs.uk/information)



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