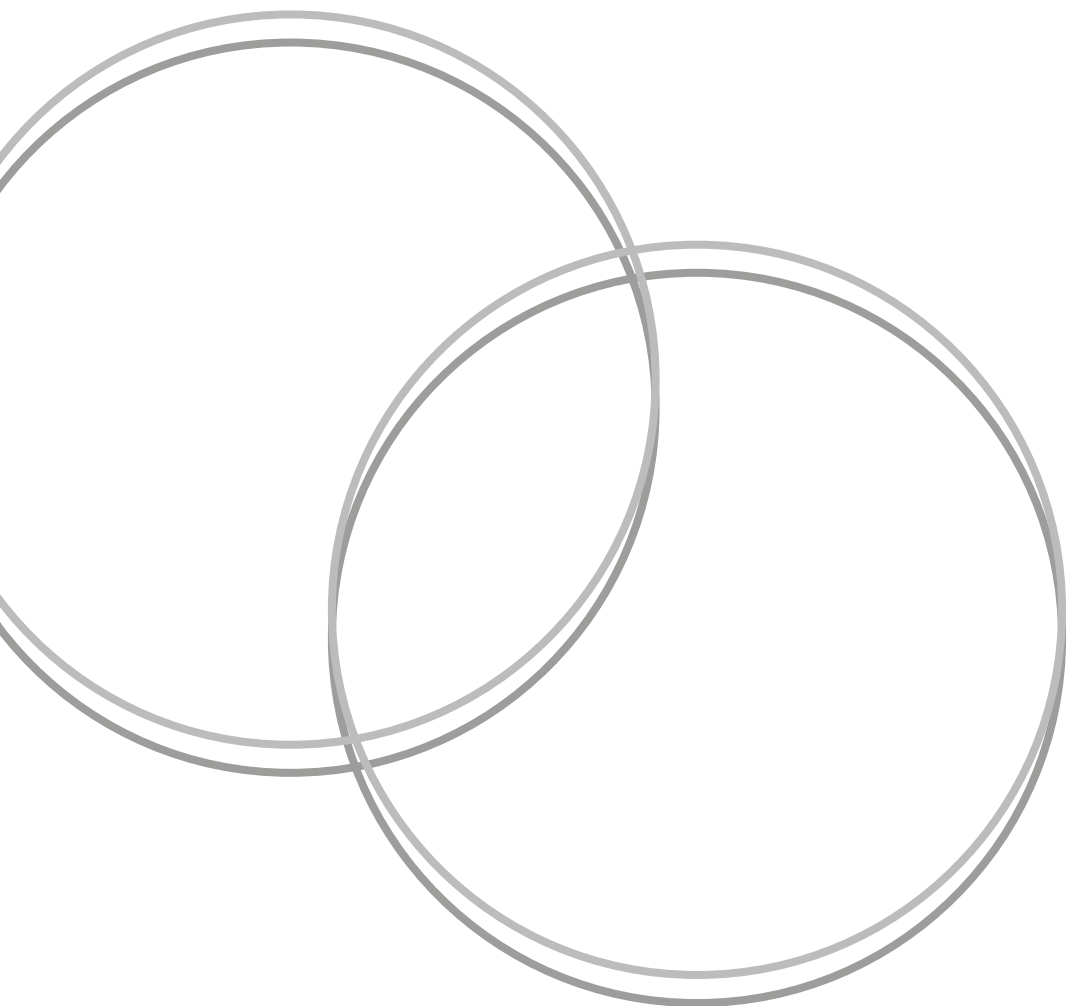




Oxford University Hospitals
NHS Foundation Trust

MGUS: when to contact your nurse specialist



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 to find out if you have noticed 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 is to tell you about these symptoms.

Symptoms to look out for

MGUS can change and cause problems for organs such as your bone marrow and your kidneys. The following symptoms might indicate a need for further investigation.

Please contact your nurse specialist if you have one or more 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, too. 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. It happens even when you are getting enough sleep.

Confusion

You may be feeling muddled a lot of the time. People close to you might notice this and be worried about it. This is usually confusion that is there most of the time, not just occasionally. 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/or bedding.

Unexplained weight loss

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

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: **lisa.ferguson@ouh.nhs.uk**
lisa.ferguson6@nhs.net

Office hours: Mon & Thurs 8am to 4pm
Weds & Fri 8am to 6pm

For more information about MGUS

<https://www.macmillan.org.uk/cancer-information-and-support/worried-about-cancer/pre-cancerous-and-genetic-conditions/mgus>

<https://www.myeloma.org.uk/understanding-myeloma/related-conditions/mgus/>

Further Information

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

Authors: 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

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