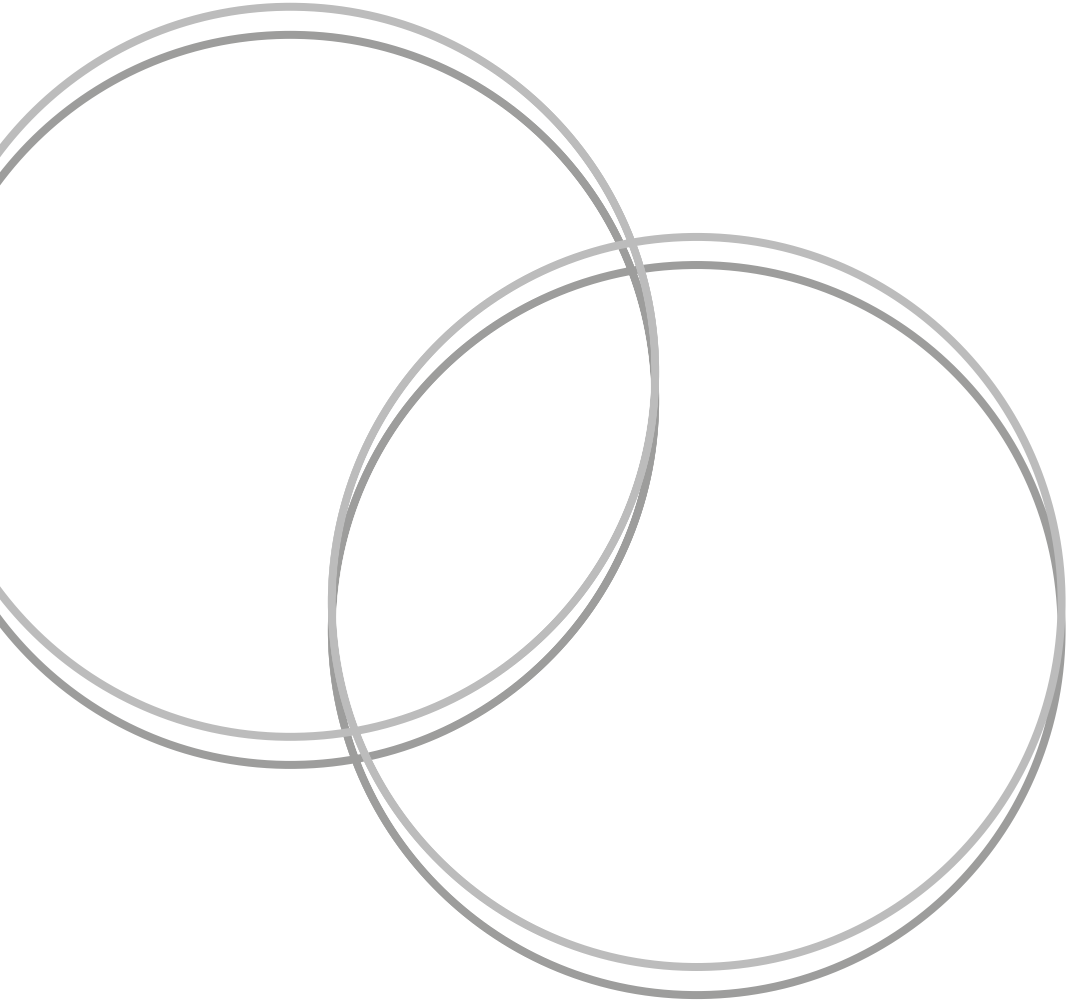
NHS

Oxford University Hospitals
NHS Foundation Trust

MGUS: Information for low risk patients



Introduction

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

This leaflet is for people who will be monitored by our Low Risk MGUS service. It will provide some information about what MGUS is, and how it is monitored.

What is MGUS?

Monoclonal gammopathy of undetermined significance, or ‘MGUS’, is a non-cancerous condition.

MGUS happens because of abnormal changes to some of the cells in your bone marrow. These cells are known as plasma cells. Normally, your plasma cells make antibodies, which help you to fight infection. The abnormal plasma cells produce an abnormal protein, known as a ‘paraprotein.’ This protein is found in your blood and sometimes in your urine.

Most people with MGUS do not know that they have it. It does not cause any symptoms.

For most people, MGUS does not cause any problems for their general health. Most people will live a normal life and never have any problems related to their MGUS.

However, sometimes MGUS changes and causes more serious conditions. These include different types of blood cancer. This is rare. It happens to about 1 person out of every 100 people with MGUS each year. Doctors do not know why it changes. There is research going on to learn more about this.

What causes MGUS?

We don’t know what causes MGUS. It is more common in older people. It is also more common in men, and more common in black people from an African background. It is more common in people with health conditions that affect their immune system, and people who have a family history of MGUS.

How is MGUS diagnosed?

MGUS is usually found when you have a blood test for something else. The abnormal proteins are found in your blood.

How is MGUS treated?

MGUS does not require treatment. You may need treatment if your MGUS changes. It is monitored with regular blood tests.

How is MGUS monitored?

You will be monitored by the Oxford University Hospitals Low Risk MGUS service.

We will offer you regular blood tests. These tests will tell your doctors whether or not anything has changed.

You will receive a letter when it is time for your next blood test. This can be taken at your GP surgery.

Your GP knows that you have MGUS. He or she has been provided with information about it.

What if something changes?

If your blood test shows that anything has changed, then your GP will refer you to the haematology department to talk about what to do next. We provide a telephone clinic for people with MGUS and other similar disorders of the blood. This is known as the OxCOM clinic. This clinic is for people who have had changes in their MGUS that might mean a higher risk of getting a more serious condition. Some people with MGUS will be referred to the OxCOM clinic for phone check-ups with our nurse specialist. Some people might need further treatment.

You should get in touch with your GP if you have any concerns about your health.

Most people with MGUS will have no physical symptoms. However, there are symptoms that might suggest a change in your condition. You should get in touch with your GP if you have any of the symptoms described below.

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 GP 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.

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.

Keeping records

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.

For more information about MGUS

Website: 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

Sacn the QR code to view a video on the Oxford University Hospitals NHS Foundation Trust OXCOM Clinic - MGUS monitoring service.

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.

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