

Smouldering myeloma

Related conditions Infosheet

This Infosheet provides information on what smouldering myeloma is, how it is diagnosed and managed, and the links between smouldering myeloma and active myeloma.

Smouldering myeloma is part of a spectrum of conditions, and is related to both active myeloma and monoclonal gammopathy of undetermined significance (MGUS).

All three involve changes to the plasma cells. These cells, normally found in the bone marrow, form part of the immune system. Normal plasma cells produce antibodies (also called immunoglobulins) to help fight infection.

What is myeloma?

Myeloma, also known as multiple myeloma or active myeloma, is a type of blood cancer arising from plasma cells in the bone marrow.

In myeloma, plasma cells become cancerous (sometimes called malignant). This means they multiply uncontrollably and produce a large amount of a single type of antibody, known as paraprotein, which has no useful function.

Paraprotein molecules are made up of two light chains and two heavy chains. In some cases, light chains can be produced without heavy chains and they are known as free light chains.

Most of the symptoms related to myeloma are caused by the build-up of the cancerous plasma cells (also called myeloma cells) in the bone marrow and the presence of paraprotein or free light chains in the body.

What is MGUS?

Monoclonal gammopathy of undetermined significance (MGUS) is a non-cancerous condition. In MGUS, low levels of paraprotein produced by abnormal plasma cells are present in the blood. Patients do not normally have symptoms but have a slightly increased risk of developing myeloma.

For more information see the [MGUS Infosheet](#) and [Myeloma – an Introduction](#) from Myeloma UK



What is smouldering myeloma?

Smouldering myeloma is an early form of myeloma that usually progresses to active myeloma, but may take some time to do so.

In smouldering myeloma, abnormal plasma cells can be detected in the bone marrow, and abnormal protein can be detected in the blood and/or urine. However, patients do not have the typical symptoms related to active myeloma, such as those associated with kidney, immune system, or bone problems.

Generally, patients with smouldering myeloma do not require treatment. However, they are monitored regularly for signs that they may be progressing to active myeloma.

In the past, smouldering myeloma has sometimes been called asymptomatic myeloma (meaning “no symptoms”). However, smouldering myeloma is different from the type of active myeloma that has no symptoms but is treated – this is explained more in the section “[How is smouldering myeloma different from active myeloma?](#)”.

How is smouldering myeloma diagnosed?

Smouldering myeloma does not normally cause symptoms, so it is often detected by chance, following a routine health check or blood tests for another condition. Blood tests may show an increased level of overall protein and this will usually prompt further tests. Patients with MGUS are regularly tested for early signs of myeloma.

To confirm the diagnosis of smouldering myeloma, tests and investigations are carried out including blood and urine tests, imaging scans and a bone marrow biopsy.

For smouldering myeloma to be diagnosed, the blood and urine tests will show:

- A blood paraprotein measurement of 30 g/L or above (and/or urinary monoclonal protein of 500 mg or more per 24 hours)
- Normal blood calcium*
- Normal kidney function*
- No anaemia*

(* unless abnormal due to some unrelated cause)

A bone marrow biopsy and imaging scan will show:

- Between 10 and 60% myeloma cells in the bone marrow
- No bone lesions

For patients to be confirmed as having smouldering myeloma, they may have either the abnormal blood/urinary protein results or the myeloma cell percentage in the bone marrow, or both.

Tables 1 and 2 summarise how MGUS, smouldering myeloma and active myeloma are diagnosed.



For more information about tests mentioned in this Infosheet, see the **Tests and investigations in myeloma Infoguide** from Myeloma UK

MGUS	Smouldering myeloma	Active myeloma
<ul style="list-style-type: none"> ● Paraprotein level in the blood of less than 30 g/L 	<ul style="list-style-type: none"> ● Paraprotein level in the blood of 30 g/L or more, and/or urinary monoclonal protein 500 mg or more per 24 hrs 	
<ul style="list-style-type: none"> ● Less than 10% myeloma cells in the bone marrow 	<ul style="list-style-type: none"> ● 10–60% myeloma cells in the bone marrow 	<ul style="list-style-type: none"> ● At least 10% myeloma cells in the bone marrow
<ul style="list-style-type: none"> ● No myeloma-defining events (see Table 2, below) 	<ul style="list-style-type: none"> ● No myeloma-defining events (see Table 2, below) 	<ul style="list-style-type: none"> ● One or more myeloma-defining events (see Table 2, below)

Table 1. How MGUS, smouldering myeloma and active myeloma are diagnosed.

Myeloma-defining events

- Hypercalcaemia: >2.75 mmol/L serum calcium
- Kidney damage: indicated by serum creatinine >177 µmol/L or creatinine clearance <40 ml/min
- Anaemia: indicated by haemoglobin <100 g/L
- Bone lesions: one or more shown on X-rays, CT or PET/CT scan
- 60% or more myeloma cells in the bone marrow
- Serum free light chain ratio 100 or more
- More than one bone lesion that is at least 5 mm or larger in size as picked up by an MRI scan

Table 2. Myeloma-defining events.

How is smouldering myeloma different from active myeloma?

Smouldering myeloma and active myeloma are complex conditions and vary from patient to patient. However, in most cases the differences are:

- Smouldering myeloma is not usually treated. Treatment is normally started when the smouldering myeloma progresses to active myeloma
- Patients with smouldering myeloma do not normally experience the symptoms seen in active myeloma that are caused by organ damage (such as bone pain or anaemia)
- Some patients have active myeloma but have no symptoms caused by organ damage. These patients are considered to have active myeloma based on their tests and scans (high levels of myeloma cells in their bone marrow, or high levels of free light chains, or more evidence of bone damage seen on scans). This is called asymptomatic active myeloma. Patients with this type of active myeloma would normally be treated

Will my smouldering myeloma develop into active myeloma?

Most patients with smouldering myeloma will progress to active myeloma at some point. However, the time this takes varies between patients, and it is not possible to say exactly when it will happen in any individual patient.

There is more about this in the section [“When will my smouldering myeloma become active?”](#)

In a few patients, smouldering myeloma will not progress to myeloma, but instead to another related condition such as AL amyloidosis.

How do I know if my smouldering myeloma is progressing?

Patients are regularly monitored for changes that may indicate that their smouldering myeloma is progressing. This will include regular blood tests and scans:

- Paraprotein and light chain
- Kidney function
- Blood calcium
- Anaemia
- Scans or bone marrow biopsy at some points

If your paraproteins increase, the haematology team will normally be looking for a gradual increase over several readings, rather than just one increased reading.

You will be monitored more often to start with after your diagnosis – for example, every three months for the first few years. Monitoring may be less often after this, if your smouldering myeloma is stable.

New symptoms may occur alongside changes in test results. It is important that you are vigilant for these, and report any to your healthcare team. Symptoms might include:



Pain



Fatigue



Loss of weight



Recurring infections



Unexpected bone breaks

What is the treatment for smouldering myeloma?

In most cases smouldering myeloma is not treated. This is because the benefits of treatment of smouldering

myeloma are still uncertain, and treatment exposes patients to potential side effects, possibly for a number of years.

Normally, treatment starts when your smouldering myeloma is developing into active myeloma. The timing of starting treatment will depend on test results, symptoms, complications and other individual factors, and will be by agreement between you and your doctor.

Clinical trials have shown that some patients with smouldering myeloma that is at higher risk of progression may benefit from starting treatment early. This is not current practice in the UK, but you may be offered treatment as part of a clinical trial or on an individual basis. If your doctor thinks this may be appropriate for you, they will discuss the option with you.

Higher-risk myeloma is explained in the next section, and research into treatment of smouldering myeloma is discussed in the “**Future directions**” section.



For information on treatment of active myeloma, see the **Infopack for newly diagnosed myeloma patients** from Myeloma UK

When will my smouldering myeloma become active?

As mentioned, smouldering myeloma is very variable and each patient is different. It is not possible to be certain when a patient's myeloma will become active.

The risk of progressing to active myeloma is lower if you have had smouldering myeloma for a long time. This has been shown by studies of smouldering myeloma patients followed up over time (see Table 3).

Causes of progression are not fully understood. However, a person's smouldering myeloma may be more likely to become active (be higher risk) if there are:

- More myeloma cells in the bone marrow
- More paraprotein or light chain in the blood
- Specific changes in the genetics of the myeloma cells

Period after diagnosis	Approximate number of patients who progressed from smouldering to active myeloma each year during this period
0–5 years	10 in 100 patients each year
6–10 years	3 in 100 patients each year
11–20 years	1 in 100 patients each year

Table 3. Approximate numbers of patients who progress from smouldering to active myeloma during different periods after diagnosis.

Coping with the diagnosis

This is often a difficult and uncertain time for patients and their families. Smouldering myeloma is even rarer than myeloma and dealing with a diagnosis can feel isolating. It can also be challenging for a patient to be told they have smouldering myeloma, but that treatment is not yet recommended.

Many patients find talking with their nurse at the hospital clinic helpful and supportive. Although you are not having treatment, you can access cancer support services at your hospital. You can also call the Myeloma Infoline on **0800 980 3332**, or join the **Myeloma Discussion Forum** and speak directly to other patients who have been diagnosed with smouldering myeloma.

To join the Discussion Forum
go to **forum.myeloma.org.uk**



Living well with smouldering myeloma

There are things that may help in living well with smouldering myeloma.

Dealing with uncertainty

It helps to recognise that a diagnosis of smouldering myeloma can have a significant impact on your emotional wellbeing, and anxiety can be worse when your regular tests are due. However, regular tests can help to reassure you that any effects of myeloma will be picked up early.

Staying positive

It is important to try and stay positive and live normally. It's OK to have some bad days, but try not to allow constant worry to take over. Complementary therapies and techniques such as mindfulness can sometimes help.

Being vigilant

Report any new symptoms such as pain, fatigue or weight loss to your clinical haematology team. It is important to get symptoms checked out, but to remember that they may not be related to myeloma.

Sources of support

You can get support from:



Your haematology team. It is always OK to ask to speak to your haematologist or your Clinical Nurse Specialist (CNS) if you are worried about any aspect of your smouldering myeloma, such as results of tests, possible progression, and timing of starting treatment



The Myeloma Infoline **0800 980 3332** and Ask The Nurse email service **AskTheNurse@myeloma.org.uk**, for information, advice or just a listening ear



Chatting with others on the Myeloma Discussion Forum **forum.myeloma.org.uk**



Family and friends – it is good to decide how many people to tell, but those you do tell can be an important source of support



Counselling or other talking therapies may help if you are finding things challenging

Future directions

An important area of research into smouldering myeloma is to understand better the underlying changes in plasma cells that cause them to become abnormal and then cancerous. This should help identify which patients are more likely to progress from smouldering to active myeloma, and who may benefit from starting drug treatment early.

A number of clinical trials of drug treatment of smouldering myeloma are taking place. These are mainly in patients at higher risk of progression. Some trials are comparing drug treatment with just monitoring the patients, while other trials are comparing different combinations of drugs.

The hope is to be able to delay progression of smouldering myeloma to active myeloma and to extend life. However, this needs to be balanced with manageable side effects because treatment may need to be given for a long time before active myeloma develops.

An approach of some other clinical trials is to look at intense treatment combinations. This research is at an earlier stage, but the ultimate aim is to eradicate the myeloma cells completely, at least in some patients.

Two studies in the UK (called COSMOS and OxPLoreD) are looking at which patients progress from smouldering myeloma and why, and looking for new markers to help identify these patients.

For an up-to-date list of UK clinical trials and studies involving smouldering myeloma patients, visit the Myeloma Trial Finder at trials.myeloma.org.uk



Key points

- Smouldering myeloma is an early form of myeloma
- Cancerous cells in the bone marrow called plasma cells produce abnormal protein called paraprotein
- Patients do not normally have symptoms
- Smouldering myeloma is usually detected by chance, and diagnosis is confirmed by tests and scans
- Most patients go on to develop active myeloma at some point, but the time taken for this to happen varies
- Smouldering myeloma is not normally treated
- Patients are regularly monitored for changes in test results, and for development of symptoms which could indicate that the myeloma is becoming active
- Living with smouldering myeloma can be very challenging but there is support available

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your healthcare team. They are the people to ask if you have questions about your individual situation.

For a list of references used to develop our resources, visit myeloma.org.uk/references

We value your feedback about our patient information.

For a short online survey go to myeloma.org.uk/pifeedback or email comments to patientinfo@myeloma.org.uk

Other information available from Myeloma UK

Myeloma UK has a range of publications available covering all aspects of myeloma and related conditions. Download or order them from myeloma.org.uk/publications

To talk to one of our Myeloma Information Specialists about any aspect of smouldering myeloma, call our Myeloma Infoline on **0800 980 3332** or **1800 937 773** from Ireland.

The Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK and Ireland.

Information and support about myeloma is also available around the clock at myeloma.org.uk



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We're here for everything
a diagnosis brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**

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Patient Information Forum

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