

Myeloma  
An Introduction



[www.myeloma.org.uk](http://www.myeloma.org.uk)

Myeloma Infoline 0800 980 3332

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## About this introduction

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This Introduction is written for patients who have been diagnosed with myeloma. It will also be helpful for their families and friends.

If you would like a more detailed overview, Myeloma UK produce a booklet called *Myeloma – Your Essential Guide*. Myeloma UK also produce a comprehensive range of Infoguides and Infosheets covering all aspects of myeloma.

If you would like to speak to someone about myeloma please call our **Myeloma Infoline on 0800 980 3332** for immediate access to practical advice and emotional support.

Your call will be answered by a Myeloma Information Nurse Specialist who is supported by medical and scientific advisors. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK. From outside the UK, call +44 131 557 3332 (charged at normal rate).

### Disclaimer

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

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## What is myeloma?

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Myeloma, also known as multiple myeloma, is a type of bone marrow cancer arising from plasma cells, which are normally found in the bone marrow. Plasma cells form part of your immune system.

Normal plasma cells produce antibodies (also called immunoglobulins) to help fight infection. In myeloma, the abnormal plasma cells release only one type of antibody known as paraprotein which has no useful function.

It is often through the measurement of this paraprotein that myeloma is diagnosed and monitored.

Unlike many cancers, myeloma does not exist as a lump or tumour. Instead, the myeloma cells normally divide and expand within the bone marrow.

Myeloma affects multiple (hence multiple myeloma) places in the body where bone marrow is normally active in an adult, i.e. within the bones of the spine, skull, pelvis, the rib cage, and the areas around the shoulders and hips.

The areas usually not affected are the extremities: that is the hands, feet, and lower arm / leg regions. This is very important since the function of these critical areas is usually fully retained.

Most of the medical problems related to myeloma are caused by the build-up of myeloma cells in the bone marrow and the presence of the paraprotein in the blood or in the urine.

## What causes myeloma and who gets it?

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The causes of myeloma are not known for certain. Exposure to specific chemicals, radiation and viruses and a weakened immune system are thought to be important trigger factors. It is likely that myeloma develops when a susceptible individual has been exposed to one or more of these factors.

Myeloma is relatively common with approximately 4,000 new cases being diagnosed each year. It mainly occurs in people over the age of 60 and affects slightly more men than women.

## What are the symptoms and complications of myeloma?

The most common symptoms and complications include:

**Bone pain:** Pain can be a symptom of the bone disease that often occurs in myeloma. The middle or lower back, the rib cage and the hips are the most frequently affected places. This pain is often persistent and described as dull and aching, and usually made worse by movement.

**Bone fractures:** The bones that most commonly fracture due to myeloma bone disease are the spine and the ribs, and breaks can occasionally occur with only minor pressure or injury. Fractures of the bones of the spine (vertebrae) can lead to collapse of the spine with associated height loss and spinal cord compression.

**Fatigue:** Persistent fatigue (an overwhelming tiredness) is often present. It may be due to the myeloma itself, to one or more of the complications of the disease, or it can be a side-effect of the treatment given.

**Anaemia:** This is a reduction in the number of red blood cells or the oxygen-carrying haemoglobin they contain. It can occur as a result of the myeloma or as a side-effect of treatment and can cause fatigue, weakness or breathlessness.

**Infections:** These are more common in people with myeloma because the myeloma interferes with the immune system making patients more susceptible to infection.

**Hypercalcaemia:** This is a condition in which the level of calcium in the blood is too high. It can occur in people with myeloma as bone disease causes too much calcium to be released from the affected bones. The symptoms of hypercalcaemia are thirst, nausea, vomiting, confusion and / or constipation.

**Kidney damage:** This can occur in people with myeloma for a variety of reasons. The abnormal protein produced by myeloma cells can damage the kidneys, as can some of its other complications, such as dehydration and hypercalcaemia. In addition, some of the drugs used to treat myeloma can sometimes cause kidney damage.

## How is myeloma diagnosed?

There are three main tests carried out to confirm a diagnosis of myeloma:

### **Paraprotein measurement**

Myeloma cells produce an abnormal protein called paraprotein. Paraprotein levels can be measured using blood, a 24 hour urine sample and a serum free light chain assay test. A high-level of paraprotein is a strong indicator of myeloma and usually reflects how active the disease is.

### **X-rays of skeleton (skeletal survey)**

Because myeloma can thin or erode the bones, one of the first investigations is likely to be a skeletal survey. This is a series of X-rays of the bones to check for bone damage.

### **Bone marrow biopsy**

This involves taking a small sample (known as a biopsy) of the bone marrow, usually from the hip bone. The sample is examined under a microscope. Normal bone marrow contains less than 5% plasma cells. People with myeloma may have between 10-90% plasma cells.

## How is myeloma treated?

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Treatment is aimed at controlling the myeloma and relieving the symptoms it causes. Although patients can live for many years with the disease, myeloma is not yet curable.

### **Active Monitoring**

Not everyone diagnosed with myeloma will need immediate treatment to control their myeloma. As treatment is only effective when the myeloma is active, it is generally not used until the disease is causing problems.

Patients who do not currently need treatment to control their disease are seen regularly by their doctors for tests to monitor their myeloma. This is called active monitoring. The options for those whose myeloma requires treatment are discussed below.

### ***Treatment to control myeloma***

#### **Chemotherapy**

This is the use of potent drugs given with the aim of destroying the myeloma cells. These drugs are given in cycles, either by injection or by mouth, over a period of months, with rest periods in between to allow the patient to recover from any side-effects.

Some side-effects are common, such as hair loss and nausea, and all side-effects vary between patients and the type of drug used. Side-effects are almost always temporary.

## **High-dose therapy and stem cell transplantation**

This involves giving very high-dose chemotherapy to destroy all the myeloma cells. Because the treatment also destroys the healthy bone marrow, stem cells (previously collected from either the patient or a donor) are used to restore the bone marrow.

## **Maintenance treatment**

This is sometimes used after chemotherapy and / or high-dose therapy and stem cell transplantation, and aims to prolong the length of time that the myeloma is kept under control.

Drugs such as interferon and corticosteroids (such as dexamethasone) have shown some benefit. Studies are trying to determine whether or not thalidomide is an effective maintenance treatment.

## ***Treatment for symptoms and complications***

The symptoms and complications of myeloma can be difficult for patients to cope with. Treatments are commonly used alongside and after chemotherapy and / or high-dose therapy and stem cell transplantation to relieve, stabilise, and in some cases, help prevent these complications.

The most frequently used of these treatments are discussed below:

**Bisphosphonate drugs** are used to minimise bone disease, hypercalcaemia and bone pain.

**Erythropoietin** is a growth factor used to stimulate red blood cell production with the aim of reversing anaemia.

**Blood transfusions** may be used to treat anaemia.

**Painkillers (analgesics)** are used to help reduce pain and generally improve quality of life. Antibiotics are often used to help the weakened immune system fight infection.

## New insights and future directions

A great deal of research is going on to help find more effective and less toxic treatments for myeloma. Many new treatments, of which thalidomide and VELCADE® (bortezomib) are examples, are now available and are being used.

Other new treatments such as the thalidomide derivative, REVLIMID® (lenalidomide) should be available in the not too distant future.

New treatments are tested in clinical studies before entering the clinic, and many people with myeloma are invited to take part in these.

As more is discovered about these new drugs and other experimental treatments, their role alongside established treatments will become clearer.

In time, if they are proved to be more effective and safer, they may replace some current treatments.

## With Myeloma UK you can...

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### **Call our Myeloma Infoline 0800 980 3332**

You will receive immediate access to information and support provided by telephone on all aspects of myeloma. Your call will be answered by Myeloma Information Nurse Specialists who are supported by medical and scientific advisors. **Open Monday to Friday, 9am to 5pm. Calls are free from the UK**

### **Get free Infopacks, Infoguides and Infosheets**

These give a range of information on all aspects of living with myeloma and related disorders with details of treatment options and disease management. They are presented in three different formats depending on the level of detail required.

### **Attend Myeloma Infodays**

These are full day educational meetings specifically for patients and their families, where you can learn about the latest in the treatment and management of myeloma from a panel of expert healthcare professionals. They also provide the opportunity to meet others affected by myeloma, to share experiences and gain support.

### **Subscribe to *Myeloma Matters***

The only myeloma specific newsletter available in the UK, *Myeloma Matters* (formerly known as *Myeloma Today UK*), offers a fantastic range of features, articles and stories to help you keep abreast of the latest developments in treatment and research.

### **Visit our website, [www.myeloma.org.uk](http://www.myeloma.org.uk)**

Myeloma UK's comprehensive and interactive website has been developed to provide you with immediate, 24 hour access to information about myeloma and related disorders.

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For more information or to access any of the information and support services listed, contact Myeloma UK

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**Annual UK Myeloma Awareness Week 21-28 June**