Myeloma UK

Myeloma
An Introduction

www.myeloma.org.uk
Myeloma Infoline 0800 980 3332

About this Introduction

This Introduction has been written for myeloma patients. It may also be helpful for their families and friends.

This Introduction aims to:

- Provide a brief overview of myeloma and its treatment
- Answer a few of the more common questions about myeloma

For more detailed information about myeloma and living with myeloma, see *Myeloma – Your Essential Guide* and *Living with myeloma – Your Essential Guide* from Myeloma UK.

To order your free copies, contact the Myeloma Infoline on 0800 980 3332. This information is also available to download at www.myeloma.org.uk

To talk to someone about any aspect of myeloma, call the Myeloma Infoline on 0800 980 3332. 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?

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 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?

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 an individual has been exposed to one or probably more of these factors.

Myeloma is relatively rare with approximately 4,000 new diagnoses 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 myeloma 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 occasionally, 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 its complications, 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.

Infection: These are more common in myeloma patients 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 myeloma patients 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 myeloma patients 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 is an indicator as to how active the disease is.

X-rays of skeleton (skeletal survey)

As myeloma can thin or erode the bones (myeloma bone disease), 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% normal plasma cells. Myeloma patients may have between 10 – 90% abnormal plasma cells.

How is myeloma treated?

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

Active Monitoring

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

Patients who do not need immediate treatment 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 outlined 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 intravenously (into a vein) or orally (by mouth in tablet form), 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 a very high dose of chemotherapy to destroy all the myeloma cells.

As this treatment approach also destroys the healthy bone marrow, stem cells (previously collected from either the patient or a donor) are re-infused (transplanted) to rescue the bone marrow.

Maintenance treatment
This is sometimes used after chemotherapy and / or high-dose therapy and stem cell transplantation and may be beneficial in certain groups of patients e.g. those whose myeloma does not respond completely to the initial 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 symptoms and complications.

The most frequently used of these treatments are outlined below:

- Bisphosphonate drugs are used to minimise and prevent myeloma bone disease, hypercalcaemia, bone pain and fractures.

- Erythropoietin is a growth factor used to stimulate red blood cell production with the aim of reversing anaemia. Blood transfusions may also 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, such as Velcade™ (bortezomib), Thalidomide Pharmion™, and Revlimid™ (lenalidomide) are now available and are being used.

New treatments are tested in clinical studies before entering the clinic, and many myeloma patients take part in these.

As more is discovered about these new and 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...

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 Specialists who are supported by medical advisors. Open Monday to Friday, 9am to 5pm. Calls are free from the UK.

Get free Infopacks, Infoguides and Infosheets
These provide a range of information on all aspects of the treatment and management of myeloma. They are presented in three different formats depending on the level of detail required. Information is also available on AL amyloidosis, MGUS, plasmacytoma and Waldenström's Macroglobulinaemia.

Attend Patient and Family Myeloma Infodays
These are full-day educational meetings specifically for patients and families, where you can learn about the latest in the treatment and management of myeloma from a panel of myeloma experts. Infodays also provide the opportunity to meet others affected by myeloma, to share experiences and gain support.

Subscribe to *Myeloma Matters*
The only myeloma-specific magazine available in the UK, *Myeloma Matters* provides a comprehensive range of features and articles to help keep you abreast of the latest developments in treatment and research as well as living with myeloma.

Visit our website www.myeloma.org.uk
A comprehensive and interactive website providing immediate 24-hour access to information about myeloma.

Join the Myeloma UK Online Discussion Group
Connect with others affected by myeloma, post messages to the group, ask questions and help to support each other. Go to **www.myeloma.org.uk** and click on discussion groups to get started.

Join a Myeloma Support Group
There are around 40 myeloma and haematology support groups in the UK. Support Groups provide an opportunity to share information and experiences with other people affected by myeloma. To find a Support Group near you, visit www.myeloma.org.uk or contact the **Myeloma Infoline on 0800 980 3332**

Published by Myeloma UK
Printed: May 2010
Last updated: November 2009

Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

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National Myeloma Awareness Week 21 – 28 June