

Myeloma – An Introduction

Myeloma Essentials

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You will find a definition of the terms highlighted in **bold** throughout this publication in the 'Medical terms explained' section on page 29.

Disclaimer: The information in this Infoguide 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.

This publication is intended for a UK audience.

It therefore may not provide relevant or accurate information for a non-UK setting.

What is myeloma?

Myeloma is a type of cancer arising from plasma cells that are normally found in the bone marrow.

Bone marrow is the soft, spongy centre of bones, where many of the body's blood cells are produced, including red blood cells, white blood cells and platelets. This includes a type of white blood cell called **plasma cells**.

Plasma cells are involved in the **immune system**. They produce **antibodies** (also known as **immunoglobulins**) which help fight infection. Normally, different plasma cells produce different antibodies to protect the body against various sources of infection.

It is these cells that become cancerous (sometimes called **malignant**) in myeloma.

Paraprotein

In myeloma, the abnormal plasma cells in the bone marrow produce a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. Paraprotein moves out of the bone marrow and into the blood. It is

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

What is 'multiple myeloma'?

Myeloma affects multiple places in the body, hence why it is sometimes referred to as 'multiple myeloma'. It affects areas where bone marrow is normally active, such as the bones of the spine, pelvis, rib cage and the areas around the shoulders and hips.

What are the symptoms and complications of myeloma?

Most of the complications and symptoms of myeloma are caused by a build-up of the abnormal plasma cells (often called myeloma cells) in the bone marrow and the presence of paraprotein in the body.

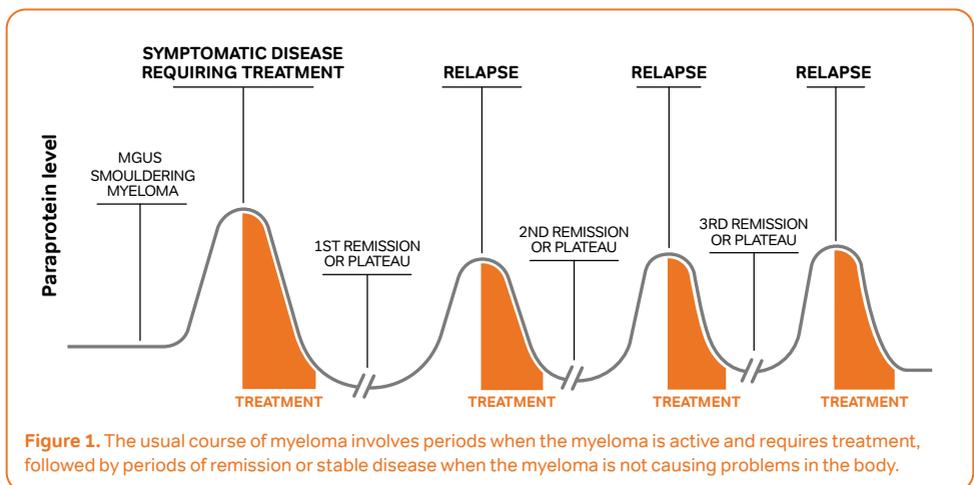
Common problems in myeloma include bone pain, bone fractures, fatigue, frequent or recurrent infection and kidney damage. These are covered in more detail on page 15.

Myeloma is highly treatable in the majority of cases. Treatment is aimed at controlling the disease, relieving the complications and symptoms it causes, and extending and improving the **quality of life**. Treatment of myeloma is covered in more detail on page 18.

While there are many effective treatments for myeloma, unfortunately it is currently incurable. This means that even after successful treatment has provided a period of **remission** or stable disease, the myeloma will return. This is called a **relapse**. See Figure 1 for an illustration of the usual pattern of progression.

Key facts

- There are approximately 5,700 people diagnosed with myeloma every year in the UK
- There are approximately 17,600 people living with myeloma in the UK at any one time
- Myeloma accounts for 15% of blood cancers and 2% of cancers generally
- Myeloma mostly affects people aged 65 and over but it has been diagnosed in people much younger



What causes myeloma?

The causes of myeloma are not fully understood but we do know that the onset of myeloma involves a complex multistep process.

Myeloma develops when **DNA** is damaged during the development of a plasma cell. This abnormal cell then starts to multiply and spread within the bone marrow.

DNA is made up of **genes** which contain the information that determine how your body develops, grows and functions. Most diseases are generally caused by a combination of different 'errors' which affect certain genes. These genetic errors are either inherited from our parent(s) or are acquired as a result of exposure to something in our environment, such as a toxic substance or virus.

Progress is being made in understanding how both inherited and acquired genetic errors cause myeloma.

However, what triggers these errors is still not known. Exposure to additional risk factors is thought to play an important role.

Risk factors for myeloma

A number of factors are associated with increasing a person's chances of getting myeloma. These include:

- **MGUS** – some people go on to develop myeloma after having been diagnosed with a condition called MGUS, which stands for **Monoclonal Gammopathy of Undetermined Significance**. It is generally now accepted that all myeloma patients have had MGUS first, whether it was identified or not

For more information see the  **MGUS Infosheet** from Myeloma UK

- **Age, gender or ethnicity** – myeloma is more common with increasing age, is twice as common among individuals of African origin than of Caucasian or Asian origin and males are 1.5 times more likely to be diagnosed with myeloma than females

- **Family history of myeloma** – people who have a close relative (parent, sibling, child) with myeloma are up to twice as likely to get myeloma than the general population
- **Weight** – obesity is a risk factor for many cancers including myeloma
- **Exposure to toxic substances** – e.g. petrochemicals, agricultural chemicals and radiation
- **Some autoimmune disorders** – e.g. rheumatoid arthritis and multiple sclerosis
- **Exposure to certain viral infections** – e.g. hepatitis, HIV and herpes virus

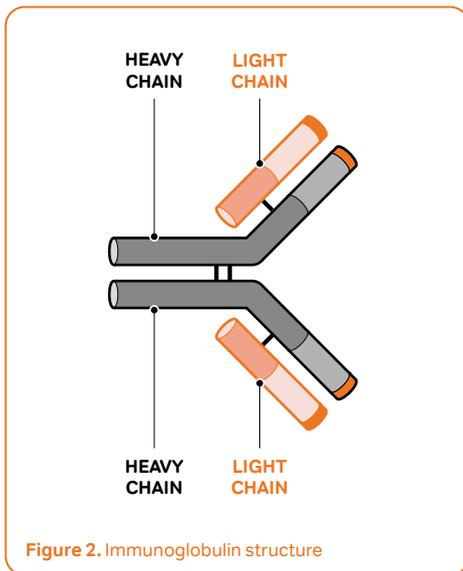
How and why these factors increase the risk of developing myeloma is not yet known.

Furthermore, the majority of myeloma patients have been associated with none of these risk factors indicating that other factors, not yet known, are also involved.

Types of myeloma

Myeloma is often described as being a very individual cancer, both in terms of the way patients experience complications and in the way they respond to treatment, which can vary greatly. Some of this variation is due to the different types and subtypes of myeloma.

The most common way myeloma can be classified is according to the type of defective immunoglobulin (called paraprotein) produced by the myeloma cell.



Types of immunoglobulin

In a healthy immune system, there are several different types of immunoglobulin. Each immunoglobulin is a Y-shaped structure and is always made up of two identical heavy chains and two identical light chains (see Figure 2).

There are five possible types of heavy chain referred to by the letters G, A, D, E and M and there are two possible types of light chain referred to by the Greek letters kappa (κ) and lambda (λ).

Each immunoglobulin (Ig for short) can have only one of the five possible heavy chain types. Therefore, immunoglobulins can be IgG, IgA, IgD, IgE or IgM.

Each Ig can then be further sub-classified depending on the type of light chain it has.

IgG type myeloma

Approximately 65% of myeloma patients have what is called IgG type myeloma, with either a kappa or lambda light chain component. IgG kappa type is the most common type of myeloma.

IgG type myeloma has all the usual features of myeloma.

Other Ig type myeloma

The next most common type is IgA myeloma. IgM, IgD and IgE type myeloma are all extremely rare.

IgA type myeloma can sometimes be associated with myeloma deposits outside of the bone (called **extramedullary plasmacytoma**), and IgD myeloma can be accompanied by **plasma cell leukaemia** and is more likely to cause kidney damage.

Light chain myeloma

In about 20% of patients, the myeloma cells only produce light chains and no whole immunoglobulins (paraprotein) at all. These are called **free light chains** (sometimes called **Bence**

Jones proteins) as they are not attached to any heavy chains which would normally make up an immunoglobulin. This type of myeloma is called 'light chain' or 'Bence Jones' myeloma.

The light chains produced by the myeloma cells are exclusively kappa light chains or lambda light chains. An increase in either kappa or lambda light chain levels in the blood can indicate active myeloma. The ratio of kappa to lambda light chains can also be calculated. An abnormal ratio can indicate active myeloma and is considered to be as important as the kappa and lambda levels for diagnosing light chain myeloma.

Of all the different types of myeloma, light chain myeloma is most likely to cause kidney damage. This is because the excessive amount of light chains circulating in the bloodstream of patients with light chain myeloma can both block the tubules (tiny tubes) within the kidney, and cause inflammation to the kidney tissue.

Light chains are also elevated and measurable in the majority of patients that produce paraprotein. This means that light chain measurement can be of use not just in patients with light chain myeloma but in all myeloma patients.

Oligosecretory and non-secretory myeloma

Extremely rarely, in less than 1% of patients, the myeloma cells produce very little or no abnormal immunoglobulin chains of any type.

Oligosecretory myeloma patients have very low measurable levels of abnormal protein (either paraprotein or light chains) in their blood or urine. 'Non-secretory' myeloma patients have no detectable levels of abnormal protein in their blood or urine.

The low or immeasurable levels of abnormal protein make it challenging for these types of myeloma to be diagnosed and monitored using traditional blood and urine tests.

A test called the serum free light chain assay (sFLC assay or Freelite® test) is able to detect minute amounts of light chains in the blood, making the diagnosis and monitoring of oligosecretory patients easier. Patients with non-secretory myeloma are generally monitored using other tests such as **bone marrow biopsies** (see page 10 for more about this and other tests and investigations used to diagnose and monitor myeloma).

Genetic subtypes of myeloma

Myeloma is associated with multiple genetic abnormalities or errors. Many of these abnormalities are within **chromosomes** (the structures in which our DNA is packaged).

It is possible to use these chromosomal abnormalities of the myeloma cells (**cytogenetics**) to group patients on the basis of their genetic subtype.

Each genetic subtype has its own distinctive features which may influence not only the onset and speed of progression of the myeloma, but also how well a patient

responds to treatment. For instance, certain genetic subtypes are associated with **high-risk myeloma**, a more active or more difficult to treat myeloma.

As such, genetic abnormalities have the potential to be useful **prognostic markers** in myeloma.

Genetic abnormalities are detected from bone marrow samples using techniques such as **fluorescence in situ hybridisation (FISH)** and **next-generation sequencing**.

It is hoped that in the future all patients will be genetically subtyped so that they can be given the best treatment for them based on their genetic profile – this represents a significant area of research in myeloma.



For more information see the **Genetics and myeloma Infoguide** from Myeloma UK

Diagnostic tests and investigations

Anyone suspected of having myeloma should be referred to a haematologist for further tests and investigations. Myeloma is a complex cancer and its diagnosis can involve a number of different tests. It is also a very individual cancer and therefore results from diagnostic tests may vary from patient to patient.

The aims of the tests and investigations are to:

- Establish a diagnosis
- Gain an in-depth picture of the specific characteristics of the myeloma
- Detect any complications so that they can be effectively managed
- Help determine a treatment plan

Bone marrow tests

Bone marrow tests are important to determine both the presence and amount of myeloma cells in your bone marrow in proportion to the other blood cells.

There are two types of bone marrow tests that may be carried out.

These involve the removal of some liquid bone marrow (a bone marrow aspirate) and/or the removal of a 1–2cm core of bone marrow tissue in one piece (a bone marrow biopsy).

The aspirate is looking at the percentage of myeloma cells present in the bone marrow. The biopsy is looking at whether the bone marrow tissue has been infiltrated by the myeloma cells. Both an aspirate and a biopsy are usually carried out at diagnosis, although not in every patient. For example, it can be quite difficult to carry out a biopsy in some patients and the doctor may make the decision to make the diagnosis with an aspirate sample alone.

Following diagnosis, most patients will rarely have another set of bone marrow tests. Non-secretory patients may have them more regularly due to the difficulties in monitoring this type of myeloma. Patients on certain clinical trials may also have them more regularly as a means of monitoring the activity of the myeloma.

Both bone marrow tests are fairly invasive procedures and must be carried out by a skilled specialist.

Bone marrow samples are usually taken from the pelvic bone (Figure 3). A needle is inserted through the skin and into the bone and a sample is drawn up through a syringe. The procedures are carried out under local **anaesthetic** with or without sedation and last only a few minutes.

The bone marrow sample may be used for genetic analysis to determine the genetic subtype of myeloma (see page 8). However, this is not yet routinely performed.

Blood tests

There are a variety of blood tests that help to diagnose and monitor myeloma.

Paraprotein level

Regular blood tests are performed to measure your paraprotein level. As well as being important in diagnosing myeloma, changes in the paraprotein level can be a good indicator of changes in the activity of the myeloma following treatment.

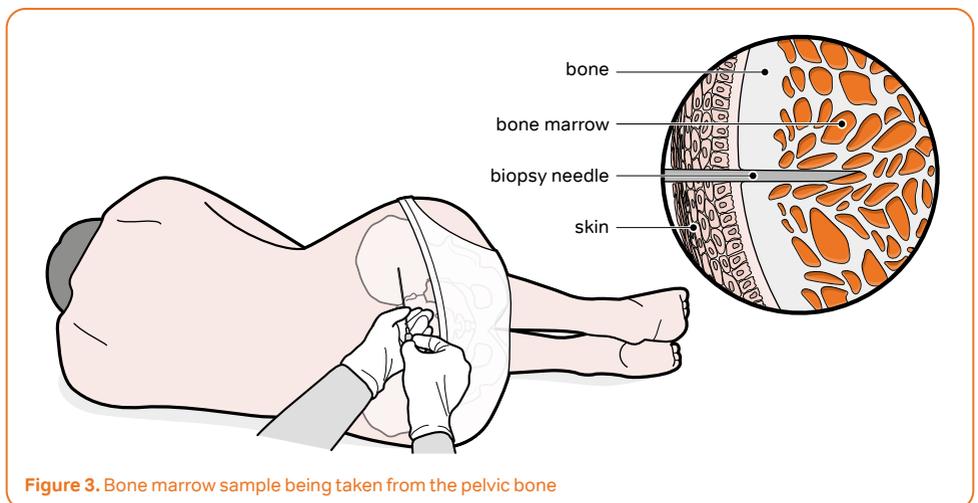


Figure 3. Bone marrow sample being taken from the pelvic bone

Serum free light chain assay

If no paraprotein is detected but myeloma is still suspected, a sFLC assay may be performed to measure the amount of free light chains in your blood. This test is particularly important in diagnosing and monitoring light chain myeloma or oligosecretory myeloma, although, increasingly, it is also being used in all patients alongside more conventional blood tests. This is because light chains are elevated and measurable in the majority of myeloma patients, and the highly sensitive sFLC assay potentially has the ability to detect changes in the activity of the myeloma sooner than conventional blood tests.

Full blood count

A full blood count measures the levels of the different cells in your blood. The most important are:

- Red blood cell count – a low count shows that you are **anaemic**
- White blood cell counts – low counts of some or all of the different white blood cells indicate that you are at greater risk of infection

- Platelet count – a low count shows that you are at an increased risk of bleeding or bruising more easily than normal

Blood chemistry

A full blood chemistry test provides an overview of the levels of various substances in your blood that can indicate the activity of the myeloma. They include:

- Beta 2 microglobulin (β 2M) – a protein that is found on the surface of almost all cells in the body. It is present in most body fluids but is increased in myeloma. β 2M is one of the most important indicators of both the amount and activity of myeloma
- Creatinine and urea – both are waste products that are normally filtered out by the kidney and passed into the urine. High blood levels of creatinine and urea indicate poor kidney function
- Albumin – a type of protein that normally makes up most of the protein found in the blood. In myeloma, chemical messengers

(**cytokines**) produced by the myeloma cells suppress albumin production

- Calcium – a mineral which is normally found in bone. In patients with active **myeloma bone disease**, a higher than normal level of calcium is released from the bone into the blood (**hypercalcaemia**)
- Lactate dehydrogenase (LDH) – a protein that is found in almost all body cells, but very little is normally in the blood. More LDH is found in the blood when cells are being damaged or destroyed

For normal ranges of test results see Appendix 1 on page 33.

Imaging tests

A skeletal survey is a series of X-rays of the long bones, spine and the skull, to detect evidence of myeloma bone disease. Areas of bone damage that show up on an X-ray are known as **lytic lesions**. X-rays can also identify any areas of bone damage which have caused the bone to fracture or collapse and which require immediate repair.

More advanced imaging tests include **magnetic resonance imaging (MRI)** or **computerised tomography (CT)** scans. These scans can provide more detail and identify areas of bone damage that are not so easily detected by X-ray.

Repeat tests

Many of these tests are repeated regularly throughout all stages of your treatment and care to measure response to treatment and monitor myeloma activity over time. Tracking the levels of normal and abnormal proteins in the blood is particularly useful and is likely to be the most frequent test you will have.

For more information see the **Tests and investigations Infoguide** from Myeloma UK



Staging myeloma

Patients are usually ‘staged’ at diagnosis and may be staged again at relapse. The most commonly used staging tool in myeloma is the Revised International Staging System (see Table 1).

Staging indicates the effect the myeloma is having on the body and can be used to help determine when treatment should begin.

Starting treatment

On completion of some or all of the tests described above, your doctor should have a clear and in-depth picture of the specific characteristics of your myeloma. The presence of complications caused by the myeloma damaging specific organs and tissues of the body can also help to determine the characteristics of your myeloma. These are commonly referred to by the

acronym ‘CRAB’, which describes the four major complications that are generally observed in myeloma:

- C** – calcium elevation
- R** – renal (kidney) damage
- A** – anaemia
- B** – bone damage

Results from the tests and investigations listed above, together with CRAB, will help determine when treatment should begin, what that treatment should be, and provide a baseline against which response to treatment and disease progression can be measured (see page 18).

Stage	Criteria	Treatment
I	<ul style="list-style-type: none"> ● Serum β2M level – less than 3.5 milligrams per litre (mg/L) ● Serum albumin level – greater than or equal to 3.5 grams per decilitre (g/dL) ● No high-risk cytogenetics ● Normal LDH 	May not be necessary
II	<ul style="list-style-type: none"> ● Not stage I or III 	May be necessary
III	<ul style="list-style-type: none"> ● Serum β2M level – greater than or equal to 5.5mg/L ● High-risk cytogenetics or elevated LDH 	Is necessary

Table 1. Revised International Staging System

The symptoms and complications of myeloma

Unlike many other cancers, myeloma can affect the body in several ways causing a number of symptoms and complications. This is due to the myeloma cells acting directly on the tissues of the body and releasing a variety of proteins and other chemicals into the bone marrow and bloodstream.

The most common symptoms and complications of myeloma, how they may affect you, and how they are managed are described in this section. Many of these symptoms and complications can be caused by the myeloma itself and by treatment for the myeloma.

It is important to remember that not everyone will experience all of these and that effective supportive treatments and strategies to prevent or control them are available.

Myeloma bone disease

Myeloma cells can interfere with the normal process of bone maintenance, a complication known as myeloma bone disease, which affects the majority of myeloma patients. It can cause areas of thinning in the bone (lytic lesions), which can lead to a variety of other complications.

Bone pain

Pain can be a symptom of bone disease. The middle or lower back, the rib cage and the hips are the most frequently affected areas. This pain is often persistent, dull and aching and is usually made worse by movement.

Bone fractures

The bones that most commonly fracture due to myeloma bone disease are the spine and the ribs. Breaks can sometimes occur with only minor pressure or injury. Fractures of the bones of the spine can lead to collapse of the spine with associated height loss and, occasionally, spinal cord compression.

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 constipation.

Low blood cell count

Myeloma cells crowd out the bone marrow, preventing the normal number of blood cells from being produced. This can lead to further complications and symptoms.

Treatment for myeloma can also cause a low blood cell count.

Fatigue

Persistent fatigue (an overwhelming tiredness) is a common symptom of myeloma and its complications. It can also be a **side effect** of the treatment given. It can be caused by anaemia stemming from a reduced red blood cell count (see below) but there may also be a number of other factors causing it.

Anaemia

This is a drop 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

This is common in myeloma patients because myeloma and its treatments can interfere with the immune system, reducing the white blood cell count, making patients more susceptible to infection.

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 hypercalcaemia. In addition, some of the drugs used to treat myeloma can sometimes cause kidney damage.

For more detailed information about any of these symptoms and complications, contact Myeloma UK



Reporting symptoms and complications

Be honest with your doctor and nurse about any problems you are having. Describing them as

accurately and as early on as possible can reduce the number and severity of the complications associated with myeloma and will help you get the right treatment, early on.

Keep a **Patient diary** from diagnosis onwards so that you can refer to it when describing your symptoms and patterns of symptoms to your doctor or nurse.

Order your free **Patient diary**
from Myeloma UK



How is myeloma treated?

Treatments for myeloma can be very effective at controlling the disease, reducing symptoms, improving quality of life and prolonging life. Unfortunately, though, there is currently no cure for myeloma.

There are two main goals in the treatment of myeloma:

- Bringing the myeloma under control, using various combinations of anti-myeloma treatments to kill myeloma cells within the bone marrow
- Improving quality of life by treating the symptoms and complications associated with myeloma, such as anaemia and bone pain

Not everyone diagnosed with myeloma will need immediate treatment. Results from various tests and investigations, together with any symptoms you may have, will help determine when treatment should begin.

Treatment for myeloma is often most effective when two or more drugs with different but complementary mechanisms of action are given together. These drugs will be given in cycles – a set pattern of treatment over a number of weeks. These cycles will

be repeated, usually for a particular number of cycles (e.g. up to 8 cycles) or for an amount of time (e.g. until the myeloma progresses), which is referred to as a course or line of treatment.

Initial treatment

This is divided into two approaches:

1. Intensive treatment for younger and/or fitter patients
2. Non-intensive treatment for older and/or less fit patients

There is no rigid age cut-off as to who gets intensive versus less intensive treatment. As a general rule, patients:

- Under 65 years old are likely to be candidates for intensive treatment
- Over 70 years old are more likely to be candidates for non-intensive treatment

- In between 65 and 70 years old will be given careful consideration as to what treatment group they fit into, depending on their overall health

Both intensities of treatment are very effective, but intensive treatment is deemed too toxic for older and/or less fit patients.

For more detailed information on all aspects of newly diagnosed myeloma, see the **Infopack for newly diagnosed myeloma patients** from Myeloma UK

All patients who require treatment will almost certainly begin with combination treatment normally involving three anti-myeloma drugs. The treatment combinations are usually made up of:

- A **chemotherapy** drug, usually either melphalan or cyclophosphamide
- A **steroid** such as dexamethasone or prednisolone
- Another drug such as thalidomide, bortezomib (Velcade®) or lenalidomide (Revlimid®)

These drugs all have different mechanisms of action and work synergistically – this means that together they are much more effective at killing myeloma cells than if they were given on their own.

Intensive treatment

In the younger and/or fitter group, initial treatment is normally referred to as ‘**induction treatment**’ as it is almost always followed by additional treatment known as **high-dose therapy** and **stem cell transplantation** (HDT-SCT).

This involves giving a very high dose of chemotherapy in an attempt to kill a greater number of myeloma cells, with the aim of inducing a longer, deeper remission than standard-dose chemotherapy.

However, as high-dose chemotherapy also destroys the healthy bone marrow, **stem cells** are re-infused (transplanted) to rescue the bone marrow. In most cases, the patient’s own stem cells are transplanted. More rarely, stem cells from a sibling or an unrelated donor are used. This is called an **allogeneic stem cell transplant**.

HDT-SCT is associated with significant side effects and can require up to a two to three week stay in hospital, followed by a three to six month recovery period. This is why it is not generally an option for older and/or less fit patients.

For more information see the **High-dose therapy and autologous stem cell transplantation Infoguide** from Myeloma UK

Less intensive treatment

In the older and/or less fit group, initial treatment is often similar to the induction treatment given in the younger and/or fitter group but some of the drugs may be given in slightly lower doses.

Relapse treatment

When the myeloma returns, another course of anti-myeloma treatment is given to get the myeloma back under control.

The options available will depend on the number of relapses that have occurred. The decision of which treatment to have will be made

by the doctor and patient, taking into consideration various factors, such as any complications, likely side effects of the treatment and previous responses.

For more information see the **Infopack for relapsed and/or refractory myeloma patients** from Myeloma UK

Treatment for refractory myeloma

Sometimes a patient may not respond to treatment, or it may stop working. This is known as being refractory. If this happens, a different treatment will be given.

Treatment for symptoms and complications

The symptoms and complications of myeloma can be difficult for patients to cope with. Supportive treatments are commonly used alongside and after anti-myeloma treatment to relieve, stabilise and, in some cases, help prevent these symptoms and complications.

The most frequently used supportive treatments are:

- **Bisphosphonates**, which are used to minimise and prevent myeloma bone disease, hypercalcaemia, bone pain and fractures
- Blood transfusions, which can be used to increase your red blood cell count if you have anaemia as a result of having a low number of red blood cells. You may also be given a drug called **erythropoietin (EPO)**, which encourages the production of new red blood cells
- Painkillers, which are used to help reduce pain and generally improve quality of life
- **Antibiotics**, antivirals and antifungals, which are used to prevent and treat infection
- **Anti-emetics**, which are used to prevent or minimise nausea and vomiting
- Surgery, which may be needed in some cases to repair or strengthen damaged bones. Fractures of the spine may be treated using one of two relatively

non-invasive surgical techniques known as percutaneous vertebroplasty and balloon kyphoplasty



For more information see the **Vertebral compression fractures in myeloma Infoguide** from Myeloma UK

How do I know if my treatment is working?

The aim of treatment is to control the myeloma and to alleviate any symptoms it may be causing. To find out how you are responding to treatment, several tests will be carried out on a regular basis.

These tests may vary from patient to patient, but generally include regular blood and/or urine testing and occasional bone marrow tests or X-rays.

The signs that treatment is working include:

- A fall in the paraprotein or light chain level
- An improvement in your symptoms and/or complications such as bone pain, anaemia and kidney function
- A reduction in the number of myeloma cells in the bone marrow
- An improvement in your general health and wellbeing

Often the trend in results can be more helpful than individual test results in showing the activity of the myeloma.

Usually, your doctor will measure your response to treatment according to the categories in Table 2.

Myeloma can respond very well to treatment and go into remission. This means that there is no sign of active myeloma in your body. Or, the paraprotein or light chain level can be reduced and remain at a stable level following treatment. This is called a **plateau** or stable disease.

It is important to note that the **duration of response** can be as important as the level of response, so both remission and plateau/stable disease are desirable treatment outcomes.

Treatment responses	Definition
Stringent Complete Response	No detectable paraprotein, normal free light chain ratio, no myeloma cells in the bone marrow
Complete Response (CR)	5% or less plasma cells in bone marrow, no detectable paraprotein
Very Good Partial Response (VGPR)	90% or greater reduction in paraprotein
Partial Response (PR)	50% or greater reduction in paraprotein
Stable Disease (SD)	Not meeting criteria for CR, VGPR, PR or progressive disease, but with stable values for at least three months
Progressive disease	25% or more increase in paraprotein or the development of new myeloma-related symptoms

Table 2. Treatment responses

Living well with myeloma

Being diagnosed with myeloma affects every patient differently. At first you might be overwhelmed, in shock and feel numb. Information may not sink in at this point but remember, you will have many opportunities to ask questions again.

Sometimes you might feel totally in control of your feelings and at other times strong emotions may catch you unawares. You may feel a great deal of fear, anger and frustration. These feelings are common and a natural part of coming to terms with the diagnosis.

Although sometimes you may feel optimistic, there may be other times when you feel overwhelmed. You may have difficulty sleeping, become irritable, or lose interest in the things that you normally enjoy. It is important to recognise these symptoms and to discuss them with your doctor or nurse.

You may also experience a sense of relief that you now have an explanation for the symptoms you have been experiencing over recent months.

Learning more about myeloma, your treatment options and life after a diagnosis of myeloma can help to ease these feelings. Those around

you may feel some of the same things you are feeling – they will also need support. Talking together about how you feel can help.

It can also help to think about the ways your diagnosis may impact your life and what you can do to minimise or prepare for the changes. This might involve thinking about your work, finances, travel and lifestyle. Being aware of potential challenges and the support available to help you through them can help you feel more prepared if you do face challenges in the future.

For more detailed information see the **Infopack for living well with myeloma** from Myeloma UK



Self-help checklist

- ❑ Learn about myeloma and its treatment – order free information from Myeloma UK or download from the Myeloma UK website myeloma.org.uk
- ❑ Join a Support Group – it can help to talk to other patients and relatives about how you feel. Find your nearest Support Group online at myeloma.org.uk
- ❑ Call the Myeloma Infoline on **0800 980 3332** or **1800 937 773** from Ireland for information and emotional support
- ❑ Find out from your GP which support services and benefits are available and ask for help if you need it
- ❑ Ask for a contact name and number for a member of staff in your medical team and keep the number handy
- ❑ Describe symptoms simply and accurately to your doctor or nurse – do not underplay them or assume they are not important. Try keeping a Patient diary of your symptoms
- ❑ Take all treatment as agreed – use a chart or a segmented pillbox (you can buy one of these at your local chemist) to help you remember what to take and when
- ❑ Bring any side effects to the attention of your doctor or nurse
- ❑ Try to drink two to three litres of fluid each day
- ❑ Put aside time for rest and relaxation; make getting enough sleep a priority
- ❑ Be aware of ongoing signs of depression and anxiety and speak to your GP about them
- ❑ Try to do something that you enjoy every day
- ❑ Think positively, but allow yourself to have ‘off days’
- ❑ If you are a carer, make sure you take care of your own health, and take some time for yourself each day

Order your free **Patient diary** from the Myeloma UK website or via the Infoline 

Myeloma research, new treatments and clinical trials

Over the past few years, new developments in the treatment and management of myeloma have had a significant impact on the way myeloma is treated.

The key goals of current myeloma research include:

- Giving each patient the best treatment for their disease-specific and individual needs
- Overcoming resistance to treatment
- Developing better drugs with fewer side effects
- Identifying new targets for treatment
- Preventing the onset and progression of myeloma
- Finding a cure

Clinical trials are key to reaching these goals and they require patient involvement. There are different types and phases of clinical trials, and each trial is designed to ask and answer specific questions about the treatment involved – for example, is this treatment safe? Is this treatment effective? Is it better than current treatments?

There is a promising pipeline of new anti-myeloma treatments currently being looked at in clinical trials, including treatments with new ways of working and new combinations of treatments currently in use.

If you are interested in taking part in a clinical trial, speak to your doctor in the first instance.

Research is also looking into the genetic changes that occur in myeloma cells. This is fundamental to understanding more about how best to treat and manage myeloma. Understanding more about the genetics of myeloma will fuel the development of new, more effective and targeted drugs and diagnostic tests that will underpin a future where treatment can be tailored to different subgroups of patients.



To keep informed about new treatments in myeloma and those in development, subscribe to our free magazine, **Myeloma Matters**, by calling **0131 557 3332** or visit myeloma.org.uk

Questions for your doctor/medical team

It can be difficult to know where to start or what questions you should ask after a diagnosis of myeloma. You may find the following list helpful to ask your medical team or they may prompt more questions of your own.

Diagnosis

- What tests will I need to have?
- When will I get the results?
- Will I need to have treatment?
- What is the treatment likely to be?
- Are my bones affected?
- Are my kidneys affected?
- Who will be my main point of contact at the hospital from now on?
- How successful has this treatment been in the past?
- Will a hospital visit/stay be needed?
- How will I feel before, during and after this treatment?
- Will there be side effects, when will I experience them and how long will they last?
- Will treatment affect my chances of having children in the future?

Treatment

- What are my treatment options?
- Can I choose which treatment to have?
- What would happen if I chose not to have this treatment?
- Is this treatment part of a clinical trial?
- How is the treatment given, how long will it take?

After treatment

- How often will I have check-ups and blood tests?
- Will I receive any supportive treatments e.g. a bisphosphonate?
- How will I know if the myeloma has come back?

Carers

Carers often have different information needs. If you are a carer you will want to know what you will need to do for your family member/friend. You may want to ask the following questions:

- Will they require a stay in hospital and for how long?
- Will they require a lot of looking after?
- What kind of quality of life do you expect them to have?
- Who can I call in an emergency?
- Are we eligible for any benefits from the Government?

For more information see the **Infopack for carers of myeloma patients** from Myeloma UK



Tips

- Carry paper and a pen with you to write down questions as they occur to you
- Give your doctor a list of the questions you have written down at the beginning of your appointment
- Take someone with you to your appointments, both as moral support and for an extra 'listening ear'
- Don't be afraid to ask for extra time to make a decision about treatment; you may want to discuss things with family and friends first
- Always tell your doctor if you are taking any medications you have bought over the counter (without a prescription), or any vitamins, supplements or complementary therapies you are using
- Tell your doctor if you are experiencing any side effects or new symptoms

Medical terms explained

Allogeneic stem cell transplant: A procedure in which stem cells from a compatible donor (usually a sibling) are given to the patient following high-dose chemotherapy.

Anaemia: A condition in which the amount of haemoglobin in the blood or the number of red blood cells is below the normal levels, causing shortness of breath, weakness and tiredness.

Anaesthetic: A type of drug used to temporarily reduce or take away sensation so that otherwise painful procedures or surgery can be performed. A general anaesthetic makes the patient unconscious and therefore unaware of what is happening. A local anaesthetic numbs the part of the body that would otherwise feel pain.

Antibiotic: A type of drug used to prevent or treat an infection caused by bacteria.

Antibodies (immunoglobulins): Proteins found in the blood produced by cells of the immune system, called plasma cells. Their function is to bind to substances in the body that are recognised as

foreign, such as bacteria and viruses (known as antigens), enabling other cells of the immune system to destroy and remove them.

Anti-emetic: A type of drug used to prevent or minimise nausea and vomiting.

Bence Jones proteins: Free light chains that have been filtered from the blood by the kidneys and are found in the urine. The presence of any Bence Jones protein in urine is abnormal.

Bisphosphonate: A type of drug that slows down or prevents bone damage.

Bone marrow: The soft, spongy tissue in the centre of bones that produces blood cells.

Bone marrow biopsy: A procedure to remove of a small sample of bone marrow tissue (for examination under a microscope).

Chemotherapy: A type of drug intended to kill cancer cells. They can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

Chromosomes: Structures in which the DNA is packaged within a cell.

Computerised tomography (CT or CAT scan): A scanning procedure that uses X-rays and a computer to create detailed images of the body.

Cytogenetics: The study of the structure and function of cells, particularly chromosomes.

Cytokine: A protein produced mainly by cells of the immune system that act as chemical messengers between cells. Cytokines can stimulate or inhibit the growth and activity of various types of cells.

DNA: Stands for deoxyribonucleic acid. A molecule that contains the instructions an organism needs to develop, live and reproduce.

Duration of response: The length of remission or plateau before relapse.

Erythropoietin (EPO): A hormone produced by the kidneys, which is involved in the production of red blood cells. Injections of synthetic erythropoietin (EPO) can be given to patients who are anaemic.

Extramedullary plasmacytoma: A collection of myeloma cells found in a single location outside of the bone.

Fluorescence in situ hybridisation (FISH): A test used to detect chromosomal abnormalities in myeloma cells.

Free light chain: A molecule which normally makes up part of an antibody. Called “free” light chain when it is not attached to the rest of the molecules that make up the antibody.

Genes: Strands of DNA which act as a set of instructions to make molecules called proteins. Together these make up the blueprint of life that determines how the body develops, grows and functions.

Haemoglobin: The protein found in red blood cells that carries oxygen around the body.

High-dose therapy: Treatment with high doses of chemotherapy given intravenously prior to patients receiving healthy stem cells as part of the stem cell transplantation procedure.

High-risk myeloma: A more active or more difficult to treat myeloma, often associated with certain genetic abnormalities.

Hypercalcaemia: A higher than normal level of calcium in the blood, which may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion.

Immune system: The complex group of cells and organs that protect the body against infection and disease.

Induction treatment: Treatment with an initial standard-dose treatment combination that patients receive before a stem cell transplant procedure. Induction treatment aims to reduce the amount of myeloma in the bone marrow before the stem cells are collected.

Lytic lesions: Damage to the bone caused by myeloma. They look like holes in the bone on an X-ray.

Magnetic resonance imaging (MRI): A scanning procedure which involves a combination of radio-waves, a powerful magnetic field and a computer to produce images

of any organ or tissue within the body. An MRI scan generates very detailed cross-sectional images of the area under investigation.

Malignant: A term for cancerous cells which have the ability to spread.

Monoclonal Gammopathy of Undetermined Significance (MGUS): A non-cancerous condition in which low levels of paraprotein are present in the blood. Patients do not have symptoms but have an increased risk of developing myeloma.

Myeloma bone disease: A complication in which bone is damaged by myeloma cells. Results in lytic lesions, pathological fractures and spinal collapse.

Next-generation sequencing: A technique that can determine the precise sequence of DNA within cells.

Paraprotein: An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease. Also known as M protein.

Plasma cell leukaemia: A cancer characterised by unusually high levels of abnormal plasma cells in the blood. It can start by itself or it can evolve from advanced myeloma.

Plasma cells: A type of white blood cell that produces antibodies (immunoglobulins) to fight infection.

Plateau: A period of time when the myeloma, and the paraprotein level, is relatively stable.

Prognostic marker: A characteristic that gives an indication of the likely progression of a disease.

Quality of life: Refers to a person's level of comfort, enjoyment, and ability to pursue daily activities. A measure of an overall sense of wellbeing.

Relapse: The point where disease returns or becomes more active after a period of remission or plateau (often referred to as stable disease).

Remission: The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Side effects: The undesired effects caused by a drug or treatment, for example fatigue or nausea.

Stem cell: A type of cell from which a variety of cells develop. Haematopoietic stem cells give rise to red blood cells, white blood cells and platelets.

Stem cell transplantation: The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

Steroid: A group of hormonal substances produced by the body. They are also produced synthetically and used to treat many conditions.

Appendix 1:

Blood tests and normal ranges

Blood tests	Test name	Normal range*	Notes
Full blood count	White cell count	4.0–11.0 $\times 10^9/L$	A low count makes you less able to fight infections
	Haemoglobin (men)	135–180 g/L	A low haemoglobin level causes anaemia and fatigue
	Haemoglobin (women)	115–160 g/L	
	Platelets	150–400 $\times 10^9/L$	A low count makes you bruise or bleed easily
	Absolute Neutrophil Count	1.5–7.5 $\times 10^9/L$	A low count makes you less able to fight infection
Urea, electrolytes and creatinine	Urea	2.5–6.7 mmol/L	Measure of kidney function
	Creatinine	70–150 $\mu\text{mol/L}$	Measure of kidney function
	Calcium (total)	2.12–2.6 mmol/L	Raised by myeloma bone disease
Proteins	Paraprotein	0 g/L	Abnormal protein found in certain conditions, including myeloma
	Total protein	60–80 g/L	Often raised in myeloma because of amount of paraprotein
	Albumin	35–50 g/L	Often lowered in myeloma because of presence of paraprotein
	Kappa (κ) light chain	3.3–19.4 mg/L	Part of an immunoglobulin (antibody). Levels are often raised in myeloma, with an abnormal ratio (normal ratio is 0.26 κ to 1.65 λ)
	Lambda (λ) light chain	5.71–26.3 mg/L	

* The normal range is an average, but each hospital laboratory has its own 'normal range' of values

Explanation of units

g/L	number of grams there are in a litre of blood
$\times 10^9/L$	number of billion cells there are in a litre of blood
mmol/L	number of thousandths of a mole** in a litre of blood
$\mu\text{mol/L}$	number of millionths of a mole** there are in a litre of blood
**mole	a standard measurement for the amount of any chemical

Please note that doctors do not use a litre of blood to make these measurements; they take a small sample (a few millilitres) and then multiply up the results.

Useful organisations

Carers UK

www.carersuk.org

0808 808 7777

Provides advice, information and support for carers.

Citizens Advice

www.citizensadvice.org.uk

England: 03444 111 444

Wales: 03444 77 20 20

Scotland: call your local office

Northern Ireland: call your local office

Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support

www.macmillan.org.uk

0808 808 0000

Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's

www.maggiescentres.org

0300 123 1801

Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind

www.mind.org.uk

0300 123 3393

Provides advice and support to empower anyone experiencing mental health problems.

NHS 111 Service

www.nhs.uk/111

111

Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

We're here for everything a diagnosis of myeloma brings



Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.



Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**



Learn about myeloma from experts and meet other patients at our **Patient and Family Myeloma Infodays**.



Order or download our **information publications**, which cover all aspects of myeloma - call **0800 980 3332** or visit **myeloma.org.uk**



Join your nearest **Myeloma Support Group** to meet up and talk to other people face to face.



Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.



Watch **Myeloma TV**, videos about myeloma presented by experts, patients and family members.



Use the **Discussion Forum** for the opportunity to share experiences and advice about living with myeloma.



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We need your help

Thanks to our generous supporters we are able to provide information and support to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.

Myeloma UK receives no government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a single donation or setting up a Direct Debit**

Online at myeloma.org.uk/donate

Over the phone **0131 557 3332**

Or by posting a cheque payable to **Myeloma UK** to:

Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG

- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness
- **Leaving a gift in your will** – legacies are an important source of income for Myeloma UK and help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments



However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 557 3332** or email fundraising@myeloma.org.uk

“

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do.

”

Judy Dewinter – President, Myeloma UK

We appreciate your feedback. Please fill in a short online survey about our patient information at myeloma.org.uk/pifeedback or email any comments to myelomauk@myeloma.org.uk

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



Myeloma Essentials:
Myeloma – An Introduction



We're here for everything a diagnosis of myeloma 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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