Myeloma bone disease and bisphosphonates

Symptoms and complications Infoguide
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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 24.

**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.
Myeloma – an overview

Myeloma is a type of cancer arising from plasma cells that are normally found in the bone marrow. Plasma cells are a type of white blood cell which form part of the immune system.

Normal plasma cells produce different types of antibodies to help fight infection. In myeloma, the plasma cells become cancerous (sometimes called malignant) and release a large amount of a single type of antibody, known as paraprotein, which has no useful function. It is often through the measurement of paraprotein that myeloma is diagnosed and monitored.

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

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.

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 for myeloma is often most effective when two or more drugs, with different but complementary mechanisms of action, are given together. Treatment is usually given over a number of weeks which may or may not be followed by a rest period. This pattern constitutes one cycle of treatment and a series of treatment cycles is referred to as a course or line of treatment.

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**.

The causes of myeloma are not fully understood but it is believed to be caused by an interaction of both genetic and environmental factors.

**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 as young as 20
What is myeloma bone disease?

Myeloma bone disease is the most common and often most debilitating feature of myeloma and bone pain is a very common symptom.

Around 70% of patients have evidence of myeloma bone disease at the time of diagnosis and approximately 90% of patients have myeloma bone disease at some point during the course of their myeloma.

Although bone is made up of minerals and is hard, it is a living tissue containing blood vessels, nerves and cells (see Figure 1).

This includes two very important cell types which play a key role in the normal activity of bones:

- **Osteoblasts** – cells which form new bone
- **Osteoclasts** – cells which break down old bone

Osteoblasts and osteoclasts work together to maintain a continuous cycle of bone formation and breakdown keeping the bone in a constant state of renewal.

![Figure 1. Bone structure](image-url)
This ongoing process is known as **bone remodelling** (see Figure 2) and maintains the thickness, strength and health of bones in the body.

Normally, the rate of bone formation and the rate of bone breakdown are equal, so that the bone mass remains the same.

In myeloma, however, the myeloma cells in the bone marrow affect the surrounding bone, causing it to be broken down faster than it can be repaired. Specifically, myeloma cells produce proteins known as cytokines and growth factors which increase the production and activity of osteoclasts (increasing bone breakdown), and at the same time reduce the activity of osteoblasts (reducing bone formation). This results in a net loss of bone and causes bones to become weaker and more susceptible to fracture.

Affected areas of bone often appear as ‘holes’ on an X-ray. These ‘holes’ are called **lytic lesions**. They represent thinned and weakened bone, increasing the risk of breaks without undue force or injury – this is called a **pathological fracture**.

![Figure 2. Normal bone remodelling](image-url)
As myeloma bone disease is the most common complication of myeloma at diagnosis, bone imaging tests will be carried out to confirm the diagnosis of myeloma (alongside blood, urine and bone marrow tests) and to decide on the need for treatment.

Some of these tests may also be repeated at times during the course of your myeloma, for example if you have non-secretory myeloma or plasmacytomas, or for investigating new bone-related symptoms at relapse.

**X-ray**

A series of X-rays, called a ‘skeletal survey’ was for many years the routine imaging test for detecting evidence of myeloma bone disease.

The skeletal survey allows large areas of the skeleton to be visualised and includes X-rays of the spine, skull, chest, pelvis and the long bones of the arms and legs.

X-rays can show areas of thinning, lytic lesions and fractures.

The X-ray procedure itself is painless, but you may be asked to lie in certain positions that may be uncomfortable or painful. It may help to take painkillers a few hours before your X-ray appointment and to use pillows and other aids to make you more comfortable when you have the X-rays.

The disadvantage of X-rays is their lower sensitivity compared to more sophisticated imaging tests, such as magnetic resonance imaging (MRI). For example, lytic lesions only show up on an X-ray when at least 30 – 50% of the bone has been lost and around 20% of myeloma patients have no abnormal findings by X-ray.

More sensitive imaging techniques are increasingly preferred to investigate bone damage in myeloma patients.

**Magnetic resonance imaging (MRI)**

MRI involves a combination of radio-waves, a powerful magnetic field and a computer to generate images of the organs and tissues of the body by picking up signals sent out by water molecules.
Unlike X-rays and CT scans, MRI does not involve the use of radiation. MRI is more sensitive than X-rays and can provide an in-depth picture of how the myeloma is affecting your bones, and where it is throughout the bone marrow.

It is now recommended that hospitals consider performing a whole-body MRI scan of people suspected of having myeloma, rather than a skeletal survey.

Whether or not you have an MRI scan will depend on your clinical situation and on which hospital you attend – not all hospitals have MRI scanners, although it is possible for you to be referred to another hospital that has an MRI scanner on site.

As MRI scans involve a powerful magnetic field, you will not be able to have one if you have a heart pacemaker or any metal implants in your body.

It is important you lie still whilst you have an MRI scan. It can take up to an hour to complete so you may find it uncomfortable to remain still for the duration. You can arrange beforehand to be sedated when you have your scan.

MRI is especially useful for:

- Assessing the amount and pattern of myeloma cells in the bone marrow (called bone marrow infiltration)
- Detecting small bone lesions
- Confirming suspected spinal cord compression
- Identifying soft tissue plasmacytomas and solitary plasmacytoma

Computerised tomography (CT) scans

CT scans combine the X-ray procedure with a specialised computer to create detailed cross-sectional images of the body. The amount of radiation used in a CT scan is greater than for an X-ray but is more sensitive and can determine the presence or absence of myeloma bone disease more accurately. Small lytic lesions that would otherwise be missed by X-ray are detectable by CT.
A CT scan may be done:

- If you have bone pain but X-rays did not reveal any bone damage and you are unable to have an MRI scan
- To visualise a part of your body which is difficult to X-ray e.g. breast bone, shoulder blade
- To confirm the presence of a soft tissue plasmacytoma
- To pinpoint the exact area where radiotherapy treatment is to be given

**PET/CT scanning**

In some cases a PET/CT will be carried out. This is where a CT scan is combined with a positron emission tomography (PET) scan.

In preparation for a PET/CT scan, radioactive sugar is injected into your vein. This is taken up by cells which require a lot of energy, such as myeloma cells.

Radioactive emissions from the sugar are then detected by the scanner which produces images of the body to show where the myeloma is.

The dose of radioactivity injected for a PET/CT scan is low and is equivalent to about as much as an X-ray.

The sensitivity of PET/CT scanning in detecting lytic lesions is broadly similar to MRI but MRI is considered to be better at detecting the extent of infiltration of the bone marrow by the myeloma cells.
What are the complications of myeloma bone disease?

Myeloma bone disease can cause a number of complications.

**Osteopenia**
Osteopenia (bone thinning) means a general loss of mineralised bone. It is common in myeloma patients and can lead to small compression fractures of the spine and fractures of the ribs, causing pain and discomfort. It is following detection of fractures like these that myeloma can sometimes be diagnosed.

**Lytic lesions**
Lytic lesions are areas in which the bone appears to have been eaten away, leaving a ‘hole’. They are most commonly found in the skull, spine, pelvis, ribs and the long bones of the arms and legs.

**Pathological fracture**
A pathological fracture is a broken bone that occurs in an area of weakened bone. It can occur spontaneously or with only slight injury, most often in the ribs, pelvis, sternum (breast bone) and the long bones of the arms and legs.

**Collapsed vertebrae, kyphosis and height loss**
When myeloma bone disease is extensive in the spine, it can result in fractures of the vertebrae. In some cases, these fractures can become compressed, cause the damaged vertebrae to collapse and lead to severe back pain (see Figure 3).

Sometimes the collapse changes the shape of the spine and makes it abnormally curved (kyphosis), resulting in a loss of height.

This can lead to varying degrees of immobility. Occasionally, breathing difficulties and eating problems occur because of the pressure the curvature of the spine places on the chest and/or abdomen.

**Spinal cord compression**
Spinal cord compression is the term used to describe pressure on the spinal cord. In myeloma, this can be caused by collapsing vertebrae or by the growth of a plasmacytoma within the spine.
If compression is slight, symptoms can include discomfort in the back, weakness, tingling and changes in sensation, often affecting the legs and arms.

If the compression is more severe, pain, numbness, significant weakness, and problems with passing urine and opening the bowels often occur.

Cord compression is serious and is regarded as a medical emergency – left untreated it can lead to paralysis. Therefore, it is important to contact your doctor immediately if you develop any of these symptoms.

**Pain**

Bone pain is the most frequent symptom of myeloma bone disease and is commonly felt in the mid and lower back, ribs and hips, or wherever there are areas of bone damage due to myeloma bone disease.

The severity and intensity of the pain varies from patient to patient but it is often aggravated by movement and relieved by lying down.

Pain sometimes gets progressively worse over time but, where it occurs suddenly and severely, it can be a sign of a fractured bone.

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**Figure 3.** Normal and fractured vertebrae
Hypercalcaemia

Bone is high in calcium and as it is broken down, a large amount of calcium is released into the blood. Once the body’s ability to maintain normal levels is overwhelmed, calcium levels in the blood remain high. This is known as hypercalcaemia.

Hypercalcaemia can cause a variety of symptoms including: loss of appetite, nausea, vomiting, constipation, increased thirst, confusion, general weakness and tiredness.

Hypercalcaemia most often presents at the time of diagnosis and is much less common once treatment has started.
Treatment and management of myeloma bone disease

Treatment of the myeloma itself is one of the most effective ways of controlling further bone breakdown, correcting hypercalcaemia and relieving pain.

In most cases, myeloma bone disease is likely to be an ongoing issue but treatments are available to slow down its activity, alleviate symptoms and sometimes correct the complications that occur.

A group of drugs called **bisphosphonates** are the central treatment of myeloma bone disease.

**What are bisphosphonates?**

Bisphosphonates are small molecules that bind to calcium and as a result are taken up into bone. They inhibit the activity of the osteoclasts and therefore interrupt the increased bone breakdown (see Figure 4).

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**Figure 4. Mechanism of action of bisphosphonates**

1. concentrated in newly mineralising bone and under osteoclasts
2. released during bone breakdown and inhibit osteoclast activity
3. reduced bone breakdown
Bisphosphonates have several potential beneficial effects, such as:

- Preventing/slowing down further bone breakdown
- Reducing bone pain and the need for painkillers
- Preventing and correcting hypercalcaemia
- Reducing the need for radiotherapy
- Reducing the likelihood of pathological fractures due to myeloma bone disease
- Improving quality of life, particularly by decreasing pain and maintaining mobility
- Improving the chances of healing and recovery of strength of bone

What are the different bisphosphonates?

There are three bisphosphonates licensed for use in the UK to treat both myeloma bone disease and the hypercalcaemia resulting from it (see Table 1).

All the different types of bisphosphonates are effective in treating myeloma bone disease and hypercalcaemia, although some may be more potent than others.

Based on the results from the Myeloma IX trial, which compared the effects of sodium clodronate against those of zoledronic acid, national guidelines now recommend all newly diagnosed myeloma patients be given zoledronic acid.

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<td>Sodium clodronate</td>
<td>Bonefos® and Loron®</td>
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<tr>
<td>Disodium pamidronate</td>
<td>Aredia®</td>
<td>Intravenous infusion over 90–120 minutes</td>
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<tr>
<td>Zoledronic acid</td>
<td>Zometa®</td>
<td>Intravenous infusion over 15–30 minutes</td>
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Table 1. Bisphosphonates used to treat myeloma bone disease
However, when discussing the different bisphosphonate options, you and your doctor may consider that an alternative one is more appropriate depending on your situation and preferences. It is important to have this conversation so that the right choice is made.

Who should and who shouldn’t receive bisphosphonates?

Current national guidelines on the diagnosis, treatment and management of myeloma recommend:

- The long-term use of bisphosphonates for all myeloma patients requiring treatment for their myeloma, whether or not they have myeloma bone disease
- Bisphosphonates should be used with caution in patients who have kidney problems
- Patients who have allergic reactions or who have a contraindication to bisphosphonate treatment should not take them

What are the potential side effects of bisphosphonates?

Bisphosphonates are generally well tolerated and any side effects are usually mild.

Fever and flu-like symptoms

These can occur shortly after intravenous infusions. They are typically mild and last for only two to three hours. The effects are usually successfully treated with paracetamol.

Vein irritation

This can occur at the site of the infusion but is usually temporary, lasting one to two days.

Nausea

This can occur the first few times oral bisphosphonates are taken but is generally mild.

Impaired kidney function

Kidney damage is probably the most important potential side effect of bisphosphonates, especially those given intravenously.
Since myeloma can already affect kidney function (e.g. due to paraprotein damage or hypercalcaemia) the possibility of kidney-related side effects of treatment is carefully monitored. Your doctor will check your kidney function regularly by a simple blood test, especially if you already have kidney problems.

To ensure the safe and effective use of bisphosphonates and to help protect the kidneys, it is recommended you maintain a high fluid intake – you should try to drink 2–3 litres of water per day.

**Osteonecrosis of the jaw**

A rare condition called osteonecrosis of the jaw (ONJ), in which the bones of the jaw become damaged, particularly after tooth extraction, appears to be related to long-term treatment with intravenous bisphosphonates. As a precaution, patients taking bisphosphonates should have regular dental check-ups and inform their doctor before any planned oral surgery/tooth extractions.

For more information about these side effects go to myeloma.org.uk

**Do bisphosphonates have an anti-myeloma effect?**

It has been suspected for some time that certain bisphosphonates may have an anti-myeloma effect. Data from the Myeloma IX trial indicates that this may be the case.

In the trial, zoledronic acid was shown to have certain benefits over sodium clodronate. The trial participants included patients with and without myeloma bone disease. Improvements in the length of remission and overall survival were seen in patients treated with zoledronic acid who did not have myeloma bone disease, as well as in those with myeloma bone disease.

This suggests that zoledronic acid may have an anti-myeloma effect in newly diagnosed myeloma patients, as well as preventing myeloma bone disease.
More research is required to further study the anti-myeloma effects of zoledronic acid. For example, although it provides potential benefits in newly diagnosed myeloma patients, it is not known whether it has the same effects in relapsed patients.

How long does bisphosphonate treatment last?

There is no rule regarding the length of time you have bisphosphonate treatment. This is usually at the discretion of your doctor but will also depend on a number of factors, for example, if you are in remission, have kidney problems or if you require dental treatment.

Generally speaking, it is recommended you have bisphosphonate treatment for a minimum of two years.

Thereafter, there is variation in practice across different hospitals in the UK. Some doctors continue patients on bisphosphonates indefinitely, some continue but reduce the frequency of administration, and some stop bisphosphonates completely and restart at relapse.

The optimal frequency and duration of bisphosphonate treatment is recognised as an area of myeloma treatment requiring further research.

Other treatments

At the moment, treatment with bisphosphonates is the standard for myeloma bone disease. However, the monoclonal antibody drug denosumab (Xgeva®) is being investigated as another potential treatment. This drug attaches to a specific protein on the surface of bone-forming osteoblasts and reduces bone breakdown.

In phase III trials, denosumab has been shown to be less toxic to the kidneys than zoledronic acid. This therefore means it may be more suitable for patients with impaired kidney function who are not able to tolerate bisphosphonates.

Denosumab is not currently licensed for use in the UK and is only available via a clinical trial.
Management of pain associated with myeloma bone disease

Bone pain is the most common symptom of myeloma bone disease. If left untreated or unmanaged, it can become debilitating and have a major impact on your quality of life.

Managing the pain associated with myeloma bone disease is therefore a priority. It is important you tell your doctor or nurse of any pain you have, describe it as clearly as possible and explain how it affects you. This way the best approach to managing your pain can be devised.

Treating the underlying problem

Pain caused by myeloma bone disease is often relieved by treatment of the myeloma itself. Responding well to anti-myeloma treatment is a major factor in reducing progression of myeloma bone disease, easing pain and improving quality of life.

Radiotherapy

Radiotherapy applied to a particular area may be helpful if you have localised severe pain. Radiotherapy can be used to relieve pain and kill myeloma cells in a specific area of bone. It can also relieve pressure on the spinal cord if myeloma cells have expanded out of the bone marrow, causing spinal cord compression, or if the vertebrae collapse due to myeloma bone disease.

Painkillers

There are many different types of painkiller (also known as analgesics) used in myeloma. They broadly fall into the following categories:

- Over-the-counter painkillers, such as paracetamol, for mild pain
- Weak opioids, such as low-dose tramadol, co-codamol and codeine, for moderate pain
- Strong opioids, such as morphine, oxycodone and fentanyl, for severe pain
- Nerve blocks, such as gabapentin, pregabalin and amitriptyline, for nerve pain

When you are taking painkillers, it is important that you find one that works best for you as no two patients are alike.
You should tell your doctor if a particular painkiller is not working or if you have side effects so that another can be tried.

It is usual to start with a low-dose or milder painkiller and increase the dose if need be, or to find the best combination of painkillers that gives a balance between sufficient pain control and tolerable side effects, such as constipation and tiredness.

Painkillers can be given in a variety of forms – by tablet, injection or patches where they are absorbed through the skin.

Non-steroidal anti-inflammatory drugs (NSAIDs) such as aspirin, ibuprofen (Nurofen™) and diclofenac (Voltarol™) should be avoided by myeloma patients, particularly those with kidney damage. Even for over-the-counter treatments, it is always best to check with your doctor regarding the best painkiller to use.

Nerve blocks such as gabapentin or pregabalin are sometimes used to help relieve pain by preventing pain signals getting to the brain.

**Surgical interventions**

These can be used to help pin or strengthen areas of bone that have fractured or are in danger of fracturing. Surgery can also be used to help treat spinal cord compression and relieve pressure on the nerves surrounding the spine.

**Percutaneous vertebroplasty and Balloon Kyphoplasty**

Percutaneous vertebroplasty and Balloon Kyphoplasty are two surgical procedures developed to treat fractures of the spine. Both procedures are normally performed by a specialist spinal surgeon or interventional radiologist and can be done either under a local or general anaesthetic.

Percutaneous vertebroplasty is used to repair a compression fracture in one or several vertebrae and to relieve pain.

It involves the injection of a small amount of bone cement through a hollow tube (cannula) into the vertebra to restore its strength. Up to two or three vertebrae can be treated at one time.
Balloon Kyphoplasty is a similar procedure but in addition to stabilising, aims to reshape and restore the height of the damaged vertebra. This is achieved by inserting a balloon into the fractured vertebra and inflating it before the cement is inserted (see Figure 5). This helps restore the vertebra to its original shape, before strengthening it with cement.

Although similar, percutaneous vertebroplasty and Balloon Kyphoplasty are not interchangeable and are indicated for different clinical situations. Therefore, doctors are very careful in deciding who might benefit from these procedures.

All surgical interventions carry some risk, so more conservative treatments for back pain will usually be tried first.

Percutaneous vertebroplasty or Balloon Kyphoplasty may then be suggested depending on the location of the pain, the type of vertebral compression fracture and the time elapsed since the fracture occurred.

The following criteria apply to both procedures when selecting patients:

- Conventional treatment for relieving bone pain such as painkillers and radiotherapy must be tried first
- Pain must have persisted for more than two months following conventional treatment
- Other causes of pain must be excluded
- Severely compressed vertebrae cannot be treated with these techniques
- These procedures must usually take place within 12 months of the collapse occurring
- You may not be suitable for treatment because of other conditions, e.g. if the collapsed vertebra is causing nerve (neurological) problems, or if you have a bleeding disorder

These procedures are not available in every NHS hospital.
However, availability is improving as more surgeons and radiologists are being trained to carry out these procedures.

For more information see the Surgical intervention in myeloma Infoguide from Myeloma UK

**Figure 5. Balloon Kyphoplasty procedure**

- a balloon is inserted into the centre of the compressed bone through a tiny tube
- the balloon is inflated, elevating the collapsed section
- the cavity is filled with bone cement
- the bone cement stabilises and preserves the re-established height
Non-medical pain relieving techniques
There are many non-medical techniques that can be used to help relieve your pain.

TENS machines
These machines transmit small electrical impulses to the body via pads stuck to the skin. There isn't a great deal of good quality scientific evidence to say for sure whether TENS machines are an effective method of pain relief. However, many people do find them helpful.

Acupuncture
Practitioners believe that the body has a system of Chi (life force) which becomes unbalanced when someone is ill. They apply needles to areas where they believe this flow has been blocked to restore balance and health.

Hot and cold compression packs
Hot water bottles and ice packs can be effective short-term pain relievers. It is best not to place them directly on the skin, and you may need to alternate between hot and cold.

Relaxation techniques
Meditation, visualisation, relaxation or a combination of these can be helpful in relieving pain.

Positioning
The way you sit or lie down can affect your pain. Move to get comfortable, use supportive pillows and ask for help from a family member or friend if you need it.

Bracing
An orthopaedic brace may sometimes be used to relieve pain associated with vertebral fractures or to stabilise areas where there is risk of fracture.

Massage
This can help with both pain and relaxation. However, make sure it is gentle and not too vigorous.

Diversion therapy
Watching TV, listening to music or chatting to a friend won't make your pain go away but it may distract your attention for a while.
Managing problems with mobility

If myeloma bone disease is causing you to have problems with your mobility, there is help and support available to help you manage.

**Exercise**

Exercise can help maintain fitness, strength and boost feelings of wellbeing. However, having myeloma may make exercise more difficult because of the effects of myeloma bone disease and also the side effects of treatment, muscle weakness and fatigue.

Although there has been limited research on the benefits of exercise in myeloma patients, studies have shown that it can help strengthen bones in osteoporosis patients.

Exercise can also benefit you in many other ways. It can boost your energy levels, reduce fatigue, help you maintain a range of movements, decrease anxiety and improve your appetite.

The type of exercise you do will depend on the extent of your bone disease and the amount of pain you have. Generally, low-impact gentle exercise, such as walking, swimming or cycling, is recommended. High-impact exercise, such as jogging, golf or contact sports, is not usually recommended.

It is important to talk to your doctor or nurse before taking part in any new exercise or sport to make sure you are not putting yourself in danger. For more specific advice, your doctor may be able to refer you to a physiotherapist.

**Help with mobility**

There are a variety of aids such as walking sticks and zimmer frames to help if you have mobility problems or if you are worried about falling. Discuss this with your GP, doctor or nurse – they can refer you to a physiotherapist or occupational therapist.

If your walking difficulties are permanent or long-term, you can get a wheelchair from the NHS. Details of local wheelchair services are available from your GP, local health centre and the physiotherapy or occupational therapy departments.
of your local hospital. Wheelchairs can also be hired from the British Red Cross (0344 871 11 11, www.redcross.org.uk) and more advice is available from organisations like the Disability Living Foundation (0300 999 0004).

**Benefits**

Personal Independence Payment (PIP) can be claimed by people aged 16–64 who are very ill or disabled and have trouble getting around or need help with day-to-day living (replacing Disability Living Allowance). You can find information on this, and other benefits, at www.gov.uk or you can contact your local Citizens Advice office for advice.

**The Blue Badge Scheme**

The Blue Badge Scheme provides a range of parking concessions for people with severe mobility problems who have difficulty using public transport. The Blue Badge enables badge holders to park close to where they need to go. The Scheme operates throughout the UK, however, parking concessions may be different depending on where you live in the UK. For more information visit www.gov.uk and search for Blue Badge Scheme.
Medical terms explained

**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.

**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.

**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 remodelling:** A normal process where old bone tissue is broken down and replaced by new bone tissue.

**Contraindication:** Term used when a treatment or procedure should not be administered to some patients. For example, drugs that can damage or stress the kidneys are contraindicated for patients with kidney damage or kidney failure.

**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.

**Interventional radiologist:** A healthcare professional who specialises in using imaging techniques to diagnose and treat diseases.

**Intravenous:** Into a vein.

**Kyphosis:** An abnormal curvature of the spine.

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

**Malignant:** A term for cancerous cells which have the ability to spread.
**Monoclonal antibody drug**: A type of synthetic drug that mimics the actions of antibodies.

**Non-secretory myeloma**: A type of myeloma in which there is no detectable paraprotein or light chains in either the blood or urine.

**Osteoblast**: Cells which form new bone.

**Osteoclast**: Cells which break down old bone.

**Osteonecrosis of the jaw (ONJ)**: A condition in which the bones of the jaw become damaged. It is a rare side effect of some types of bisphosphonate treatment.

**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.

**Pathological fracture**: A break in a bone caused by bone disease or bone cancer, rather than by trauma.

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

**Plasmacytoma**: A localised build-up of myeloma cells found either inside the bone (intramedullary plasmacytoma), or outside the bone (extramedullary plasmacytoma).

**Quality of life**: A term that refers to a person’s level of comfort, enjoyment, and ability to pursue daily activities. It is 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).

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

**Solitary plasmacytoma**: A discreet, single mass of abnormal plasma cells which can occur in bone or in soft tissue.

**Vertebra**: A bone which forms part of the spine.

**White blood cells**: A type of blood cell involved in the body’s immune system, which help to fight infection and disease.
## Useful organisations

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Website</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td><strong>Carers UK</strong></td>
<td><a href="http://www.carersuk.org">www.carersuk.org</a></td>
<td>0808 808 7777</td>
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<tr>
<td>Provides advice, information and support for carers.</td>
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<tr>
<td><strong>Citizens Advice</strong></td>
<td><a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></td>
<td>England: 03444 111 444</td>
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<tr>
<td>Wales: 03444 77 20 20</td>
<td></td>
<td>Scotland: 0808 800 9060</td>
</tr>
<tr>
<td>Northern Ireland: call your local office</td>
<td></td>
<td>Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.</td>
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<tr>
<td><strong>Macmillan Cancer Support</strong></td>
<td><a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a></td>
<td>0808 808 0000</td>
</tr>
<tr>
<td>Provides practical, medical and financial information and support to all cancer patients and their carers.</td>
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<tr>
<td><strong>Maggie’s</strong></td>
<td><a href="http://www.maggiescentres.org">www.maggiescentres.org</a></td>
<td>0300 123 1801</td>
</tr>
<tr>
<td>Provides free practical, emotional and social support to people with cancer and their family and friends.</td>
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<tr>
<td><strong>Mind</strong></td>
<td><a href="http://www.mind.org.uk">www.mind.org.uk</a></td>
<td>0300 123 3393</td>
</tr>
<tr>
<td>Provides advice and support to empower anyone experiencing mental health problems.</td>
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<tr>
<td><strong>NHS 111 Service</strong></td>
<td><a href="http://www.nhs.uk/111">www.nhs.uk/111</a></td>
<td>111</td>
</tr>
<tr>
<td>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.</td>
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</tbody>
</table>
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.
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](http://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 – Chair, Myeloma UK (2006–2018)
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