MyelomaUK

Myeloma bone disease

Symptoms and complications Infoguide

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You will find a definition of the terms highlighted in **bold** throughout this booklet in the 'Medical terms explained' section on page 30.

Disclaimer: The information in this Infoguide is not meant to replace the advice of your healthcare 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

This section explains some key facts about myeloma, including what it is, how it affects patients, and how it is treated. If you are newly diagnosed this section can be a good place to start. If you have been living with myeloma for some time, this information might be familiar but it can still be a useful reminder before reading about specific aspects of myeloma.

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, some of the plasma cells become cancerous (sometimes called **malignant**) and usually 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.

Sometimes, myeloma cells produce only part of the paraprotein, known as **light chains**. These also have no useful function. In other types of myeloma, the myeloma cells only produce small amounts of paraprotein or no paraprotein at all. There are other ways to diagnose and monitor these types of myeloma.

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

Most of the complications and symptoms of myeloma are caused by a buildup of the cancerous myeloma cells in the bone marrow and the presence of paraprotein or light chains 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 most 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.

Myeloma is known as a relapsing and remitting cancer: patients are treated and generally go into **remissions** when their cancer is not active and often is not being treated, followed by **relapses** when the myeloma is active and needs treatment again. Remissions can last for long periods of time, and many patients have a number of remissions and relapses during their lifetime. Although myeloma is not currently curable, the outlook for patients has improved greatly over recent years and is continuing to improve. There are a large number of treatments available, and others are being developed in clinical trials.

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 5,900 people diagnosed with myeloma every year in the UK
- There are over 24,000 people living with myeloma in the UK at any one time
- Myeloma is the third most common type of blood cancer, and accounts for 2% (1 in every 50) of all new cancer cases diagnosed each year
- Although more common in older people, around a quarter (1 in 4) myeloma patients are diagnosed under the age of 65

What is myeloma bone disease?

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

Around 3 in every 4 patients have evidence of myeloma bone disease at diagnosis. Around 9 out of 10 patients have myeloma bone disease at some point during the course of their myeloma.

Bone is a living tissue containing blood vessels, nerves and cells (see Figure 1). This includes two 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.

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 an overall 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**.

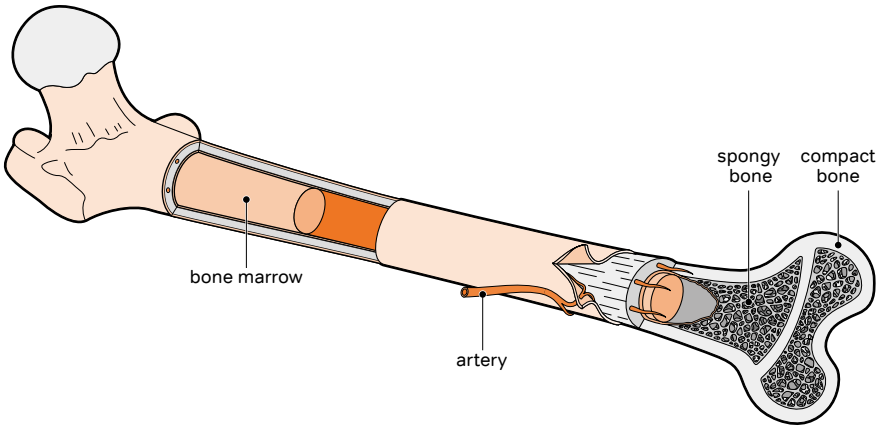


Figure 1. Cross-sectional diagram of the different structures within bone

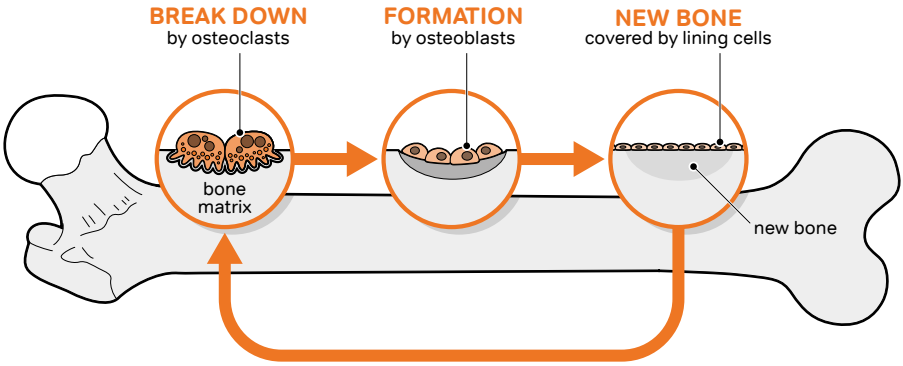


Figure 2. Normal cycle of bone remodelling

Imaging tests to detect and monitor myeloma bone disease

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 bone imaging tests may also be repeated at times during the course of your myeloma, for example if you have **non-secretory myeloma** (a type of myeloma where paraprotein and light chain can't be measured in the blood) or **plasmacytomas**, (localised buildup of myeloma cells in the bone or elsewhere). Imaging may also be done to investigate 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 that they are less sensitive than newer 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 for investigating 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, including the bones.

MRI (and CT) scans are the most sensitive ways to detect bone damage in myeloma. MRI scans can provide a detailed picture of how the myeloma is affecting your bones, and where it is throughout the bone marrow.

UK guidelines recommend that MRI scanning of the whole body should be the preferred imaging method to diagnose myeloma and to assess bone disease, if it is suitable for the patient.

As MRI scans involve a powerful magnetic field, you will not be able to have one if you have a heart pacemaker or metal implants in your body. Modern joint replacements are often safe in an MRI scanner – your doctor will be able to advise you.

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. If you think this may be a problem, speak to the department in advance of the 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 (sometimes called CAT 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. However, the scan 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. More recently, a scan called a whole-body low-dose CT (WBLDCT) scan has been developed which uses a lower dose of radiation.

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 (such as the breast bone or 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**.

Before the scan, you will be given a form of liquid sugar to which a small amount of radioactivity has been added. This is called a tracer. The sugar 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 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.

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

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. Sometimes it is fractures like these that lead to myeloma being diagnosed.

Lytic lesions

Lytic lesions are areas in which the bone appears to have been eaten away, leaving 'holes' on the affected area. 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

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, causing the damaged vertebrae to collapse. This can lead to severe back pain (see Figure 3).

This collapse can occur in several vertebrae at the same time. Collapsed vertebrae can have a number of effects, including spinal cord compression and kyphosis, which are explained in the next two sections.

For more information see the **Managing spinal fractures in myeloma Infoguide** from Myeloma UK

Spinal cord compression

Spinal cord compression is the term used to describe pressure on the spinal cord, causing damage to the nerves. In myeloma, this can be caused by collapsing vertebrae or by the growth of a plasmacytoma within the spine.

Symptoms of spinal cord compression can include:

- Back pain
- Numbness, weakness or tingling in your legs and arms
- Problems with walking
- Problems with passing urine and opening the bowels

Spinal cord compression is a medical emergency – left untreated it can lead to paralysis. If you unexpectedly develop any of these symptoms, you should seek medical advice immediately.

Kyphosis and height loss

Sometimes collapsed vertebrae change the shape of the spine and make it abnormally curved. This is known as **kyphosis** and causes the top of the back to look more rounded than usual, resulting in loss of height.

Kyphosis can lead to varying degrees of immobility and changes to day-to-day life. Occasionally, breathing difficulties and eating problems occur because of the pressure the curvature of the spine places on the chest and abdomen. You may have difficulty lifting heavier objects.

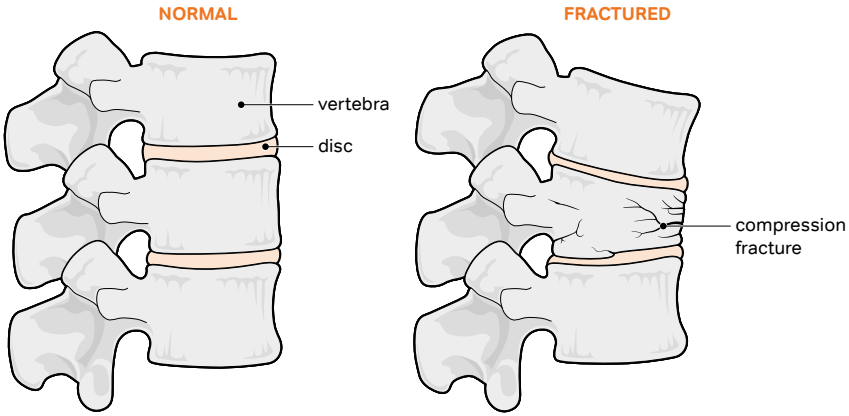


Figure 3. Normal and fractured vertebrae

The changes to your physical shape can affect your self-image. They may also require practical changes such as clothes to fit the altered shape of your back. You may find it helpful to use cushions in the home or when travelling to minimise pain caused by sitting for long periods.

Pain

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. Your healthcare team may describe this as 'bone pain'.

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. However, pain that occurs suddenly and severely can be a sign of a fractured bone.

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 and vomiting

Constipation

Increased thirst

Confusion

General weakness and tiredness

Prolonged hypercalcaemia can cause damage to the kidneys.

Hypercalcaemia is most often found at diagnosis and is much less common once treatment has started.

Myeloma bone disease during remission and relapse

When you are in remission, you may have to continue managing the complications of myeloma bone disease which developed during active myeloma. For example, you may need to take painkillers to manage ongoing pain. You will also need to be cautious of the increased risk of pathological fractures if you have existing bone damage.

During this time, your myeloma will be monitored regularly to ensure that a relapse is detected as early as possible. This helps to make sure treatment can be started as soon as it is needed, before problems from bone disease become severe.

If you are in remission and you experience any new pain (such as in your back or ribs), or symptoms such as nausea, excessive thirst or unusual fatigue, you should inform your healthcare team as soon as possible.

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. However, treatments are available to alleviate symptoms, slow down bone breakdown and correct the complications related to bone disease.

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

What are bisphosphonates?

Bisphosphonates are small molecules that bind to calcium and are taken up into bone. They reduce the activity of the osteoclasts and therefore interrupt the breakdown of bone which is usually increased in myeloma (see Figure 4).

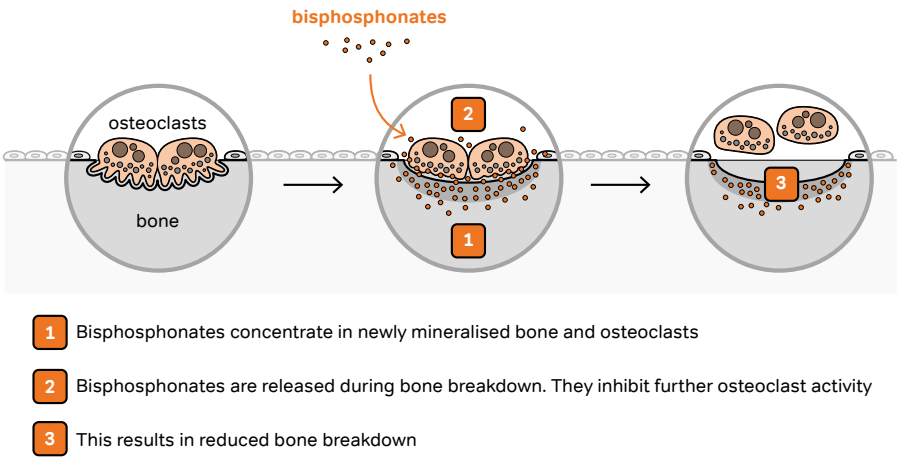


Figure 4. Mechanism of action of bisphosphonates

Bisphosphonates have several potential beneficial effects, such as:

- Preventing or 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

Bisphosphonates do not produce new bone formation, or repair existing lytic lesions. Therefore patients may still have remaining bone damage caused by their myeloma while they are in remission.

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).

Drug	Other names	How is it given?
Zoledronic acid	Zometa®	Intravenous infusion over 15–30 minutes, repeated every 3–4 weeks
Pamidronate disodium	Aredia®	Intravenous infusion over 90–120 minutes, repeated every 4 weeks
Sodium clodronate	Loron®, Clasteon® and Bonefos®	Oral tablets, taken once or twice per day

Table 1. Bisphosphonates used to treat myeloma bone disease

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.

However, you and your doctor may consider that a different bisphosphonate treatment 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 receive bisphosphonates?

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

- The 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 to bisphosphonates 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 short in duration.

Vein irritation or swelling

These can occur at the site of the infusion but are usually short in duration.

Digestive symptoms

Nausea can occur but is generally mild. Oral bisphosphonates can also cause irritation of the oesophagus (upper digestive tract). If you experience difficulty swallowing, or new symptoms of indigestion or heartburn, tell your healthcare team.

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, 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.

To ensure the safe and effective use of bisphosphonates and to help protect the kidneys, you will be advised to drink plenty of fluids – likely to be 2–2.5 litres per day.

For more information see the **Myeloma and the kidney Infoguide** from Myeloma UK

Eye complications

If you experience any eye symptoms such as redness, itching, soreness or blurred vision, let your healthcare team know straight away.

Ear complications

If you have ear pain, discharge or signs of an ear infection, let your healthcare team know straight away.

Unusual thigh bone fracture

Some people on bisphosphonate treatment may experience an uncommon type of bone fracture

called an **atypical femoral fracture**. This is occurs when the thigh bone breaks in a way that is unusual, and often without obvious force or injury. This type of fracture is more likely to occur if you have taken bisphosphonates for a long period of time.

If you experience any pain in your thigh, hip or groin area while on bisphosphonate treatment, let your healthcare team know straight away. You may be asked to complete some additional bone scans to investigate the cause of the pain.

Osteonecrosis of the jaw

An uncommon but serious side effect in some patients treated with bisphosphonates is called **osteonecrosis of the jaw (ONJ)**. In ONJ the bones of the jaw are damaged and don't heal for a prolonged period. The symptoms include non-healing tooth sockets or exposed bone in the mouth.

The risk of ONJ seems to be higher in patients taking intravenous bisphosphonates, and after longer-term treatment. Invasive dental treatments (such as tooth extractions, implants and oral surgery) also increase the risk of ONJ, although routine dental procedures such as fillings and caps should not.

These are things you can do to help reduce the risk of ONJ:

- Have a dental check-up and X-ray, and have any necessary invasive dental work done, before starting bisphosphonates
- Visit your dentist regularly for check-ups
- Maintain good mouth care
- Invasive dental procedures should be avoided if possible during bisphosphonate treatment
- Tell your healthcare team about any dental work you do need

If invasive dental work is unavoidable it should be done in collaboration with an oral surgeon experienced in ONJ. You may be taken off bisphosphonates for a period and restarted once healing is complete.

For more information see the **Osteonecrosis of the jaw (ONJ) Infosheet** from Myeloma UK

If you do develop ONJ, your doctor may temporarily stop your bisphosphonate treatment until the ONJ resolves.

Do bisphosphonates have an anti-myeloma effect?

Data from the Myeloma IX trial indicates that certain bisphosphonates may have an anti-myeloma effect.

In the trial, zoledronic acid was shown to have certain benefits over sodium clodronate. The trial participants included patients both 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 you and 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.

After this, there is variation in practice across different hospitals in the UK. Some doctors continue patients on bisphosphonates indefinitely, some continue but reduce how often it is given, 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 comparative 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 general use in the UK, but some patients may be given it on an individual basis or as part of a clinical trial.

You must speak to your doctor before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements. This is to ensure it is safe to do so and will not have any harmful effects when taken alongside bisphosphonates or other prescribed treatments.

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, but it can be successfully managed.

Managing the pain associated with myeloma bone disease is a priority. It is important you tell your healthcare team 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 severe pain in a particular area. 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 and caused 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 co-codamol and dihydrocodeine, for mild to moderate pain that is not controlled by non-opioid painkillers
- Strong opioids, such as morphine, oxycodone and fentanyl, for moderate to severe pain
- Other drugs, such as **gabapentin** 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 unmanageable side effects so that another can be tried.

It is common to start with a low dose or milder painkiller and increase the dose if needed, and to find the painkiller that gives a balance between sufficient pain control and tolerable side effects, such as constipation and tiredness.

If you are continuing to have problems with pain or side effects despite trying different treatments, ask to be referred to your local pain specialist team for further help.

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

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

Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Nurofen®), diclofenac (Voltarol®) and high-dose aspirin should be avoided by myeloma patients, because they can worsen kidney damage. Even for over-the-counter treatments, it is always best to check with your doctor or pharmacist regarding the best painkiller to use.

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.

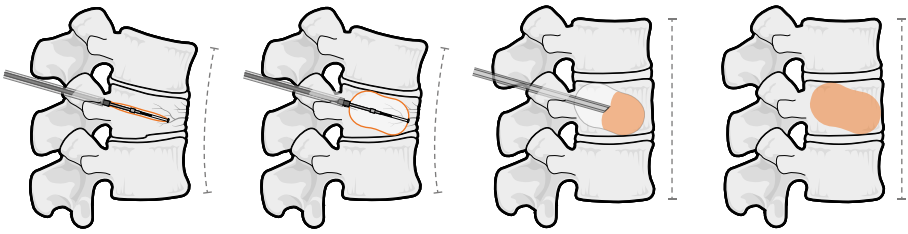
Percutaneous vertebroplasty and **balloon kyphoplasty** are two surgical procedures developed to treat fractures of the spine. Both procedures are normally performed by a specialist spinal surgeon or **interventional radiologist** and can be done either under a local or general **anaesthetic**.

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 strengthen it. Up to two or three vertebrae can be treated at one time.

Balloon kyphoplasty is a similar procedure but in addition to stabilising spinal fractures, it 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 one may be more suitable than the other in certain situations. Therefore, doctors are very careful in deciding who might benefit from these procedures.



A small keyhole cut (incision) is made in the patient's back. A balloon is inserted into the centre of the compressed bone through a tiny tube.

The balloon is inflated, lifting the collapsed section.

The balloon is deflated and the resulting cavity is filled with bone cement. A stent (a kind of splint) may also be inserted to support the repair.

The bone cement stablises and preserves the re-established height.

Figure 5. The balloon kyphoplasty procedure

All surgical interventions carry some risk, so non-surgical 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.

Your doctor will consider whether:

- Non-surgical treatment for relieving bone pain (e.g. painkillers) has been tried first
- Pain has persisted for more than 2 months following conventional treatment
- Other causes of pain have been excluded
- The vertebrae are not too severely compressed
- The procedures will be taking place within 12 months of the collapse occurring

The surgical procedures may not be the best option in some cases, for example if the collapsed vertebrae are very unstable or heavily collapsed, or if there is compression of the nerves around the spinal cord, or if you have underlying conditions such as low blood counts.

These procedures are not available in every NHS hospital, so you may be referred to another hospital which has suitable facilities.

For more information see the **Managing spinal fractures in myeloma Infoguide** from Myeloma UK

Non-medical pain relief techniques

There are many non-medical techniques that can be used to help relieve pain.

Not all these treatments are suitable for all patients, and you should ask your healthcare team for advice before starting a new treatment.

TENS machines

Transcutaneous electrical nerve stimulation (TENS) machines transmit small electrical impulses to the body via pads stuck to the skin. TENS machines are not suitable for everyone, and some patients should not use them, so you should seek advice first.

Acupuncture

Acupuncture is a treatment derived from ancient Chinese medicine. Fine needles are inserted at certain sites in the body for therapeutic or preventative purposes.

Acupuncture is used by many people to relieve pain. However, you should keep in mind that myeloma patients are at an increased risk of infection compared to other people who may undertake acupuncture, so you should always seek medical advice beforehand.

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.

Mind-body therapies

Mind-body therapies such as meditation, visualisation, relaxation or a combination of these can be helpful in relieving pain.

Correct positioning

The way you sit or lie down can affect your pain. Move to get comfortable, use supportive pillows and ask to see a **physiotherapist** for advice if you need it.

Bracing

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

Gentle massage

Gentle massage can be used to relieve muscle pain and tension and can be both therapeutic and relaxing. Tell the massage therapist that you have myeloma and that forceful massage may be damaging.

Diversion therapy

Watching TV, listening to music or chatting to a friend can help by distracting your attention from pain for a while.

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

Managing problems with mobility

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

Exercise

Exercise can help maintain fitness and strength, and boost feelings of wellbeing. It can also boost your energy levels, reduce fatigue, help you maintain a range of movements, improve your balance, decrease anxiety and improve your appetite.

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.

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 running, tennis or contact sports, is usually not 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.

For more information on exercises suitable for myeloma patients, see the **Exercises for myeloma patients Infosheet** from Myeloma UK

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 (**redcross.org.uk**,

0300 456 1914). Advice about different aids to help with daily living is available from organisations like Living Made Easy (**livingmadeeasy.org.uk**, 0300 999 0004).

Benefits

Personal Independence Payment (PIP) can be claimed by people aged over 16 and under State Pension age who have a health condition or disability and have trouble getting around or need help with day-to-day living. You can find information on this, and other benefits, at **gov.uk** or you can contact your local Citizens Advice office for advice. If you live in Scotland, you will need to apply for Adult Disability Payment instead.

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 **gov.uk/apply-blue-badge** (**nidirect.gov.uk** in Northern Ireland).

For more information see the **Benefits and financial support Infosheet** from Myeloma UK

Future directions

The process of bone remodelling is complex, with different cells producing proteins that interact with each other and with other cells.

A large amount of research is taking place, which aims to improve our understanding of how bone remodelling works in normal bone, and how it is disrupted in myeloma.

This will help to identify possible new treatments for myeloma bone disease, targeting the process at different points. The ultimate aim is to both reduce bone breakdown and stimulate repair and rebuilding of bone. A number of possible treatments of different kinds are being investigated, and some of these are being studied in early stage trials in patients.

Existing myeloma treatments also have direct effects on myeloma bone disease. These treatments include **proteasome inhibitors** such as **bortezomib (Velcade®)** and **immunomodulatory drugs** such as **thalidomide**. Researchers are trying to increase their understanding of these effects and how they could be better harnessed.

Another important area of research is into bone pain in myeloma, which is aiming to understand better how different patients are impacted.

Top 10 tips for living with myeloma bone disease

1. Try to keep mobile and take regular gentle exercise
2. Ask for a referral to physiotherapist if needed
3. Avoid over-exertion and heavy lifting to reduce risk of fractures
4. Be alert for symptoms of spinal cord compression
5. Have a dental check-up before starting bisphosphonates
6. Maintain good mouth care
7. Avoid major dental treatment during bisphosphonate treatment if possible
8. Try different pain relief until you find one that suits you
9. Ask to be referred to a specialist pain clinic if you need to
10. Make use of non-medical techniques, such as gentle massage and relaxation, which may help

Medical terms explained

Amitriptyline: An anti-depressant drug that can be used to treat neuropathic pain.

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.

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, enabling other cells of the immune system to destroy and remove them.

Atypical femoral fracture: An uncommon type of pathological bone fracture where the thigh bone breaks in an unusual way.

Balloon kyphoplasty: A procedure used to repair or stabilise a compression fracture in one or more vertebra and to relieve pain. It involves reshaping the vertebrae using an inflatable balloon before filling with bone cement.

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.

Bortezomib (Velcade®): A proteasome inhibitor drug which is given as a subcutaneous injection.

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

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

Gabapentin: An anti-epileptic drug that can be used to treat neuropathic pain.

Growth factor: A protein produced by the body that stimulates the development and growth of cells. Growth factors can also be made synthetically and given as a treatment in some circumstances.

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.

Immunomodulatory drug (IMiD): A type of drug used to act on the body's immune system.

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

Intravenous (IV): 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 imaging scan.

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 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.

Non-steroidal anti-inflammatory drug (NSAID): A type of drug used to prevent or treat pain or inflammation, which do not contain steroids. Examples are ibuprofen and diclofenac. NSAIDs should not be used in myeloma because they can worsen kidney damage.

Occupational therapist: A healthcare professional who helps patients improve their ability to do

everyday tasks if they have physical difficulties resulting from injury, illness, disability or ageing.

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 an uncommon but serious side effect of bisphosphonate treatment.

Pamidronate disodium (Aredia®): A bisphosphonate drug which is given by intravenous infusion.

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.

Percutaneous vertebroplasty: A procedure used to repair or stabilise a compression fracture in one or more vertebrae and to relieve pain. It involves injecting bone cement into the vertebra to stabilise and strengthen it.

Physiotherapist: A healthcare professional who treats patients with physical difficulties resulting from injury, illness, disability or ageing. They work with patients to identify and improve their movement and function.

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

Plasmacytoma: A localised buildup of myeloma cells found either inside the bone (bone plasmacytoma), or outside the bone (extramedullary plasmacytoma).

Positron emission tomography (PET scan): A scanning procedure which detects radiation given off by a short-lived 'radiotracer' which is injected into the body before the scan.

Proteasome inhibitor: A type of drug which interferes with the normal functioning of part of a cell called the proteasome, which is involved in the removal, breakdown and recycling of damaged or no longer needed proteins.

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.

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.

Sodium clodronate (Loron®, Clasteon® or Bonefos®): A bisphosphonate drug which is given orally.

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

Spinal cord compression: The term used to describe pressure on the spinal cord. It can be caused by a collapsed vertebra or by the growth of a plasmacytoma within the spinal canal.

Thalidomide: An immunomodulatory drug which is given orally.

Vertebra: A bone which forms part of the spine.

Zoledronic acid (Zometa®): A bisphosphonate drug which is given by intravenous infusion.

Useful organisations

Carers UK carersuk.org
0808 808 7777
Provides advice, information and support for carers.

Citizens Advice citizensadvice.org.uk
adviceni.net
England: **0800 144 8848** Wales: **0800 702 2020**
Scotland: **0800 028 1456** Northern Ireland: **0800 915 4604**
Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support macmillan.org.uk
0808 808 0000
Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's maggies.org
0300 123 1801
Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind mind.org.uk
0300 123 3393
Provides advice and support for anyone with mental health problems.

NHS 111 Service 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.

Samaritans samaritans.org
116 123
Listening and support free, 24 hours a day, to anyone who's struggling to cope.

We're here for everything a diagnosis of myeloma brings

Myeloma UK provides information and support to help you and to connect you with others with shared experiences.

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; with videos, news and articles to help you keep up to date and live well with myeloma.

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

Get answers to your questions by emailing our Myeloma Information Specialists at **AskTheNurse@myeloma.org.uk**

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

Learn about myeloma from experts and meet other patients at our **Infodays** and **Digital Infoday Sessions**.

Join a **Myeloma Support Group** to meet other people living with myeloma face to face or online.

Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of myeloma.

Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.

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 core 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 230 0429**
  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 230 0429** 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 **patientinfo@myeloma.org.uk**

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

Symptoms and complications Infoguide:
Myeloma bone disease

MyelomaUK

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

Trusted Information Creator
Patient Information Forum

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