

Bone Disease and Bisphosphonates



Myeloma Infoguide Series



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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.

askthenurse@myeloma.org.uk

Introduction

This Infoguide is written for myeloma patients, their families and friends. It provides information on why myeloma bone disease may occur, how it is diagnosed and monitored and how it is managed and treated.

Some of the more unusual or technical words appear in bold the first time they are used and are described in the glossary of medical terms at the back of the Infoguide.

Aims of this Infoguide

- To help you understand more about bone disease in myeloma
- To help you understand more about treatment with bisphosphonate drugs
- To provide answers to questions you may have about bone disease
- To help you make informed treatment decisions

Myeloma UK provides a range of specific Infoguides and Infosheets which cover all aspects of the treatment and management of myeloma. You will find a list of these at the back of this Infoguide.

If you would like a more general overview of what myeloma is, how it is diagnosed, the most commonly used treatments and many of the things you may have to cope with in living with myeloma, please see *Myeloma - Your Essential Guide* and *Living with Myeloma - Your Essential Guide*. To order your free copies contact the **Myeloma Infoline on 0800 980 3332**. This information is also available 24/7 on our website at www.myeloma.org.uk

If you would like to talk to someone about any aspect of myeloma, its treatment and management, call the Myeloma Infoline on 0800 980 3332. Your call will be answered by Myeloma Information Nurse Specialists who are supported by medical and scientific advisors. The Myeloma Infoline is open Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK. From outside the UK, call +44 131 557 3332 (charged at normal rate).

What is myeloma bone disease?

Bone disease is the most common and often the most debilitating feature of myeloma and therefore bone pain is a very common symptom. Between 70% and 80% of patients have evidence of bone disease at the time of diagnosis and most patients will experience bone disease at some point in their illness.

Bone disease is due to the myeloma cells in the bone marrow affecting the surrounding bone, causing the bone to be broken down faster than it can be repaired. The extent of bone disease varies considerably in individual patients. It most often occurs in the middle or lower back, the hips and the rib cage. The long bones of the upper arm and leg can also be involved.

Affected areas of bone often appear as 'holes' on an X-ray. These 'holes' are called **lytic lesions**. Lytic lesions can cause thinning and weakness in the bone causing it to break without undue force or injury – this is called a pathological fracture (see Figure 1 below).



Figure 1 - Lytic lesion / bone fracture

It is uncommon to develop lytic lesions or fractures in the hands or feet. This is very important since the function of these critical areas is usually fully retained.

The thinning of the vertebrae (bones of the spine) can also result in fractures. When vertebrae fracture they tend to become compressed and collapse. This is known as a compression fracture. Compression fractures result in loss of height and curvature of the spine as well as pain.

Occasionally, patients develop just one isolated lesion or lump called a **solitary plasmacytoma of bone**. This condition can be effectively cured with radiotherapy, although a small number of patients with this abnormality may develop myeloma much later on.

In very rare instances, there is an increase rather than a decrease in the formation of new bone affected by myeloma cells. This is termed **osteosclerotic myeloma**.

In order to understand more about why bone disease occurs in patients with myeloma, and the mechanisms that lie behind it, it is necessary to understand normal activity within the bone.

For more information on plasmacytoma, please see Myeloma UK's Infosheet *Plasmacytoma*. To order your free copy, contact the **Myeloma Infoline on 0800 980 3332**.

Normal activity of bone cells

Bones are made up of a strong outer shell of mineralised bone with softer, spongier bone, in the middle (see Figure 2). The outer portion of bone is called the bone cortex, while the centre of the bone is called cancellous bone. The bone marrow is contained within the spaces of the cancellous bone.

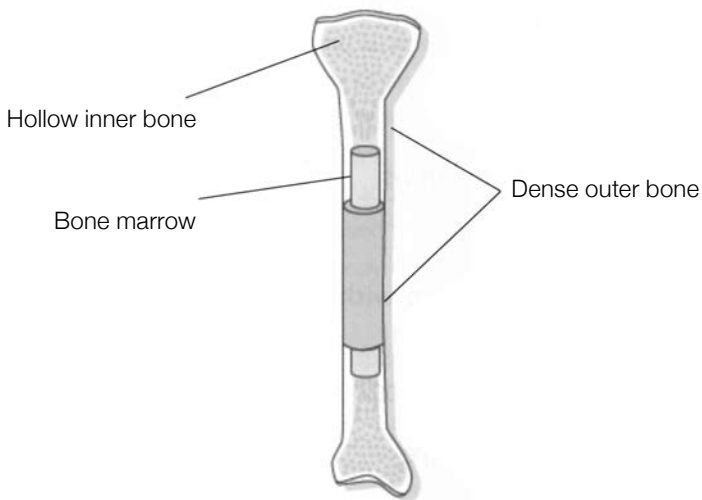


Figure 2 - Bone marrow

Although bone is made up of minerals and is hard, it is still a living tissue containing blood vessels, nerves and cells, including two very important cells which control the normal activity of bones – these are:

- Osteoblasts (cells which form new bone)
- Osteoclasts (cells which eat away old bone)

The activity of these bone cells keeps the bone in a continual state of renewal.

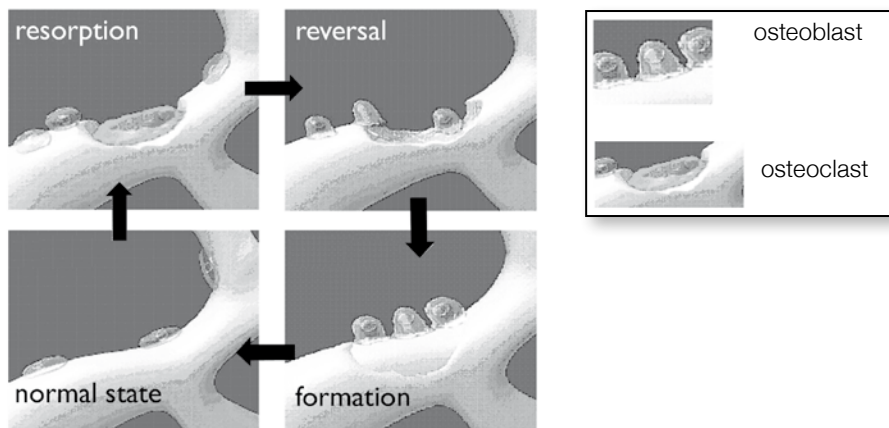


Figure 3 - Normal bone remodelling

This ongoing process is known as bone remodelling (see Figure 3) and maintains the thickness, strength and health of bones throughout the body.

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

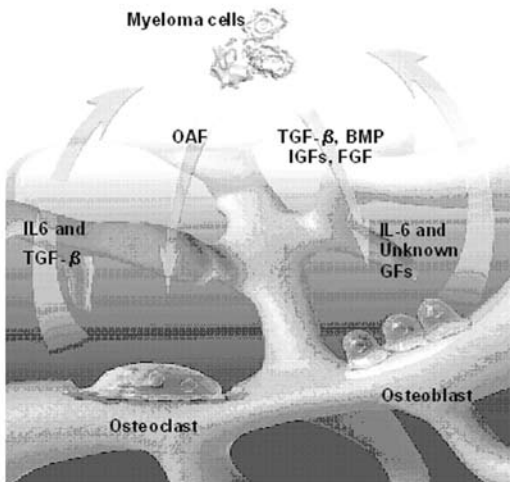
As you will see in the next section, myeloma can interfere with this process resulting in myeloma bone disease.

Bone cell activity in myeloma

Myeloma cells cause bone destruction by producing signals and substances known as cytokines that activate bone breakdown and inhibit new bone formation.

Specifically, these signals and cytokines (see Figure 4) increase the activity of the osteoclasts (cells that breakdown bone) and at the same time reduce the activity of osteoblasts (cells that build bone).

At the same time, the osteoclasts produce factors that stimulate the myeloma cells to grow, especially IL6. This results in a vicious cycle of dependency between the myeloma and bone cells in what is called the bone marrow microenvironment. It is these processes that result in bone loss and lytic lesions in myeloma.



IL-6	Interleukin 6
OAF	Osteoclast activating factor
TGF-b	Transforming growth factor beta
IGF's	Insulin-like growth factors
FGF	Fibroblast growth factors
BMP	Bone morphogenetic proteins

Figure 4 - Signalling process

Tests and investigations to detect and monitor myeloma bone disease

As mentioned earlier, bone disease is the most common presenting symptom at diagnosis. Because of this, investigations looking for bone involvement will normally be done with blood, urine and bone marrow tests to help make the diagnosis and decide on the need for treatment. Some of these tests are repeated during treatment and follow-up.

Common tests and investigations to look at myeloma bone disease include:

X-ray

Standard X-rays are the most common test used to detect evidence of myeloma bone disease. A series of X-rays, called a 'skeletal survey', is usually performed.

This survey 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, and remain the 'gold standard' for detecting myeloma bone disease.

If the skeletal survey using X-rays does not show up any area of damage, but bone disease is suspected, other imaging techniques may be used. Such techniques can also provide more detail of a particular area if required.

These additional imaging techniques include:

Magnetic Resonance Imaging (MRI)

MRI may be used if X-rays are inconclusive or more detailed testing is needed of an area such as the spine (see Figure 5 on page 8). MRI uses computerised measurements of radio waves, which enable a detailed view of the bone marrow. MRI does not involve radiation.

MRI of the spine showing bone marrow within the vertebrae

Normal marrow is bright and abnormal areas are dark



Figure 5 - MRI in myeloma

Computerised tomography (CT) scans

CT scans can be used when detailed evaluation of a small area of suspected bone damage is required or in detecting **plasma cell** involvement in soft tissue. They can also be used to pinpoint the exact area where radiotherapy treatment is to be given.

FDG / PET scanning

Whole body FDG / PET (fluoro-deoxyglucose positron emission tomography) is a relatively new, albeit less routine scanning technique in which a low-level radioactive drug is injected, which shows up areas of pronounced sugar metabolism.

FDG / PET scanning can show the difference between healthy and abnormal tissue, and can detect myeloma outside the bone marrow.

Initial research results suggest that it may be useful for monitoring purposes, especially in **non-secretory myeloma**, where there is no detectable paraprotein in the blood or urine.

What are the effects of myeloma bone disease?

Myeloma bone disease can have the following effects on the body and the skeleton:

Osteopenia

Osteopenia, (or bone thinning), which means a general loss of mineralised bone, is common in myeloma patients. Osteopenia can lead to small compression fractures of the spine and fractures of the ribs, causing pain and discomfort. It is at this stage that myeloma may often be first diagnosed.

Collapsed vertebrae / kyphosis / height loss

The bones that make up the spine (vertebrae) can also have holes, which may cause collapse in a more dramatic way than the smaller vertebral stress fractures caused by osteopenia. Sometimes the collapse changes the shape of the spine (kyphosis) and causes loss of height.

Lytic lesions

In addition to osteopenia, or bone thinning, myeloma can also cause lytic lesions which are most commonly found in the skull, spine, pelvis, ribs and the long bones of the arms and legs (see Figure 1 on page 2).

Pathological fracture

Fractures can occur spontaneously or with only slight injury in the ribs, pelvis, sternum (breast bone) and the long bones of the arms and legs (see Figure 1 on page 2).

Spinal cord compression

This is a complication that sometimes occurs due to an area of myeloma in the spine causing pressure on the spinal cord. This can occur either suddenly or slowly over time.

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 – left untreated it can lead to paralysis, so it is important to contact your doctor immediately if you develop any of these symptoms.

Hypercalcaemia

As bone is broken down, calcium is released into the blood stream overwhelming the body's ability to maintain normal levels. A high calcium level in the blood is known as **hypercalcaemia**. It can cause symptoms of tiredness, loss of appetite, nausea, vomiting, constipation, increased thirst, confusion and general weakness.

As these symptoms are somewhat general, it is easy to put these effects down to the myeloma or its treatment. Hypercalcaemia can be present at the time of diagnosis but is a much less common problem once treatment is started, now that patients receive regular bisphosphonates.

Pain

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

The intensity of the pain experienced varies from person to person. It is usually aggravated by movement and relieved by lying down.

Pain can slowly get worse over time or occur suddenly and severely, which can be a sign of a fractured bone.

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 some cases, bone disease continues to be a problem although there are treatments available that can slow down its activity, alleviate symptoms and sometimes correct the complications that occur.

The treatment of bone disease in myeloma has been revolutionised in recent years by a group of drugs called bisphosphonates.

These and other treatments are discussed over the next few pages.

Bisphosphonates

Bisphosphonates are small inorganic molecules that bind to calcium, and as a result are taken up into bone. They inhibit the activity of the osteoclasts and interrupt the increased bone breakdown.

Bisphosphonates therefore have several beneficial effects including:

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

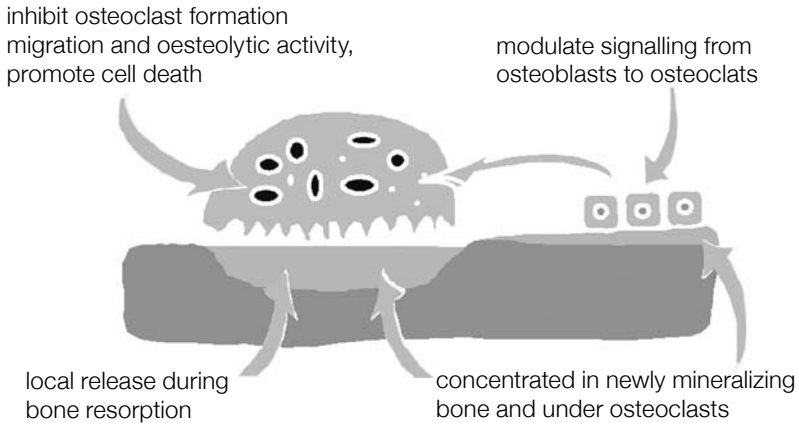


Figure 6 - Mechanisms of action of bisphosphonates

What are the different types of bisphosphonates?

There are three bisphosphonates licensed for use in myeloma in the UK to treat both the bone disease and the hypercalcaemia due directly to the myeloma.

These are shown in Table 1 on page 13 together with the method of administration.

What are the side-effects of bisphosphonates?

Bisphosphonates are generally well tolerated. Any side-effects are usually mild and the most common ones are nausea, fever, flu-like symptoms, upset kidney function and skeletal pain.

Table 1 – Bisphosphonates available in the UK

Type	Other names	Administered
Sodium clodronate	BONEFOS® and Loron	Oral tablets, taken once or twice per day
Pamidronate	AREDIA®	IV infusion over 90–120 minutes every month
Zoledronic acid	ZOMETA®	IV infusion over 15 minutes every month

Fever and flu-like symptoms can occur shortly after the intravenous infusion. They are typically mild and last for only two to three hours. The effects are easily treated with paracetamol.

Vein irritation may occur at the site of the infusion. Again, it is usually mild and patients recover within one to two days.

General bone aches and pains sometimes occur and are mostly linked to the onset of fever and / or flu-like symptoms. They can persist for a day or two after each infusion and can be managed with simple analgesics (painkillers) such as paracetamol.

Nausea that is mild and short lasting is quite common with oral bisphosphonates.

Upset kidney function is probably the most important potential side-effect. All three bisphosphonates can potentially harm kidney function. Since myeloma can affect kidney function (e.g. due to paraprotein damage or hypercalcaemia) the possibility of kidney related side-effects is of particular concern. Your doctor will check your kidney function regularly by a simple blood test.

To ensure the safety and effectiveness of bisphosphonate drugs and to help protect the kidney, you need to make sure that you maintain a high fluid intake – drinking at least three litres of water a day.

Be aware that certain medications can increase the risk of upset kidney function when given with bisphosphonates. Non-steroidal anti-inflammatory drugs, especially drugs which include Ibuprofen (Nurofen), should be avoided. Examples of other drugs that cause problems are thalidomide and some antibiotics - check with your doctor or nurse for any new medication recommended.

Pain and poor healing in the jaw (known as osteonecrosis of the jaw), particularly after tooth extraction, have been reported in a small number of cases. It is not yet certain if this is related to the bisphosphonate treatment but, as a precaution, patients should have regular dental check-ups and inform their doctor before any oral surgery / tooth extractions.

For more information on managing side-effects, please see Myeloma UK's Infosheets *The Kidney* and *Mouthcare and Myeloma*. To order your free copy, contact the **Myeloma Infoline on 0800 980 3332**.

Who should and who shouldn't take bisphosphonates?

Current national guidelines on the diagnosis, treatment and management of myeloma recommend long-term bisphosphonates for all patients with myeloma requiring treatment for their disease, whether or not bone lesions are evident.

At present, it is not certain whether patients who have no need for myeloma therapy at diagnosis and no evidence of myeloma-related bone disease, would benefit from bisphosphonates. This means that, in general, bisphosphonates are not currently recommended for patients with monoclonal gammopathy of undetermined significance (**MGUS**) and **smouldering myeloma** without bone disease. However, this remains an area of ongoing research and clinical study.

As mentioned previously, bisphosphonates should be used with extreme caution in patients who have significant renal impairment. Finally, patients who have allergic reactions or are intolerant to bisphosphonates treatment should not take them.

Which one should I take?

Although the different types of bisphosphonates have different potencies, they are all effective in treating myeloma bone disease.

There is currently no substantial evidence to suggest that one bisphosphonate is more effective than any other. Therefore, the choice of bisphosphonate used is usually down to local practice and / or patient preference.

Do bisphosphonates have an anti-myeloma effect?

The effectiveness of bisphosphonate drugs in treating myeloma disease has led to research into whether bisphosphonates have any anti-myeloma activity.

Laboratory studies that have taken place so far show that some of the newer bisphosphonate drugs, such as pamidronate and zometa might:

- Reduce production of interleukin 6 (IL-6), a growth factor that promotes the growth and survival of myeloma cells
- Induce apoptosis (programmed cell death) in human myeloma cell lines grown in the laboratory
- Exert anti-myeloma effects in animal models

Currently, the only evidence showing an increased survival with bisphosphonate treatment is from a study where a subset of patients who received pamidronate had a small survival advantage. This could however have occurred by chance.

Further large randomised studies will be necessary to establish fully whether there is indeed a survival benefit from using bisphosphonates.

The Medical Research Council Myeloma IX study that is currently taking place is looking at the use of bisphosphonates. It is a **Phase III** study and compares the use of an oral bisphosphonate (clodronate) with one of the newer bisphosphonates (Zometa).

For more information, please see Myeloma UK's Infoguides *MRC Myeloma IX* and *Clinical Studies*. To order your free copies, contact the **Myeloma Infoline on 0800 980 3332**.

Management of pain associated with myeloma bone disease

Treating the underlying problem

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

Radiotherapy

Radiotherapy applied to a particular area may be helpful for people with localised severe pain. Radiotherapy kills off the myeloma cells in the bone, which in turn reduces bone pain. Pain relief from radiotherapy is sometimes more rapid than with chemotherapy, and is often the initial treatment given.

Following radiotherapy, the bone will begin to recover by the laying down of more calcium, possibly resulting in the bone becoming slightly stronger than before.

For more information, please see Myeloma UK's Infosheet *Radiotherapy*. To order your free copy, contact the **Myeloma Infoline on 0800 980 3332**.

Pain-killing drugs (analgesics)

There are many different types of pain-killers used in myeloma and they broadly fall into the following categories:

- Mild pain-killers, e.g. paracetamol
- Pain-killers for moderate pain, e.g. dihydrocodeine
- Pain-killers for severe pain e.g. morphine and fentanyl
- Pain-killers for nerve-type pain e.g. gabapentin, amitriptyline

When using pain-killers, it is important to find the one that works best for you, as no two patients are alike. It is usual to start with a low-dose or a milder pain-killer and increase to the optimum dose, which gives a balance between sufficient pain control and tolerable side-effects.

Pain-killers can be given in a variety of forms - by tablet, injection and patches, where the medication is absorbed through the skin. Non-steroidal anti-inflammatory drugs (NSAIDs) such as Ibuprofen (Nurofen) and Diclofenac are common pain-killers, but should ideally be avoided in patients with myeloma, particularly those with kidney dysfunction.

Even for over-the-counter medicines, it is always best to check with your myeloma specialist regarding the best pain-killer to use.

Surgical interventions

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

Nerve blocks are sometimes used to help relieve pain by preventing pain signals from getting to the brain. A long-lasting anaesthetic, freezing or heat can also be used.

Percutaneous vertebroplasty and balloon kyphoplasty

Two new surgical procedures known as percutaneous vertebroplasty and balloon kyphoplasty have been developed to repair painful fractures of the spine, relieve pain and correct kyphosis caused by myeloma bone disease.

These procedures are normally performed by a specialist spinal surgeon or an **interventional radiologist**, and can be done under either local or general anaesthetic.

Percutaneous vertebroplasty involves injection of a small amount of acrylic material (bone cement) through a hollow tube (cannula) into the vertebra in order to restore its strength. Up to two or three vertebrae can be treated at one time.

Balloon kyphoplasty involves an extra step in the procedure, whereby a balloon is first inserted into the fractured vertebrae and inflated before inserting the cement (see Figure 7). This helps restore the vertebrae to their original shape, correcting kyphosis before strengthening with cement.



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 reestablished height

Figure 7 - Balloon kyphoplasty

Careful selection of the patients who might benefit from percutaneous vertebroplasty or balloon kyphoplasty is important:

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

As percutaneous vertebroplasty and balloon kyphoplasty are new procedures, they are not yet available in every NHS hospital although more and more doctors are being trained to carry out these procedures every year and availability is improving all the time.

Guidelines are available from NICE (National Institute of Clinical Excellence) on the use of vertebroplasty and kyphoplasty. These are available on the NICE website - www.nice.org.uk

For more information, please see Myeloma UK's Infoguides *Percutaneous Vertebroplasty* and *Balloon Kyphoplasty*. To order your free copies, contact the Myeloma Infoline on 0800 980 3332.

Non-medical treatments

There are many non-medical interventions that can be used to help relieve your pain. The most common of these include:

TENS machine and acupuncture: These techniques are used to stimulate nerves reaching the brain, which makes the body release its own pain-killers, called endorphins. They can be useful in treating specific areas of pain.

Hot and cold: 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 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 will distract your attention for a while.

Getting things off your chest: Anxiety and stress can make pain feel worse. Try to talk about your worries and concerns with those who are close to you, or if you prefer, talk to a professional counsellor.

Managing problems with mobility

Exercise

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

As far as we are aware there have been no studies to examine the effects of exercise on bone thinning in myeloma patients, but studies have shown that exercise has an important part to play in the prevention and treatment of osteoporosis.

There have been a few studies on exercise training for myeloma patients. One study found that myeloma patients undertaking an exercise programme showed decreased fatigue and improved sleep patterns, with no injuries caused by exercise.

The type of exercise that can be done will depend of the severity of your condition and the amount of pain you are experiencing. Generally, low impact exercise, such as walking, swimming or climbing stairs is recommended.

High impact exercise, such as jogging or contact sports, is not usually recommended. It is important to talk to your doctor or nurse before starting any new exercise or sport, just to make sure you are not putting yourself in danger.

For more specific advice, seeing a physiotherapist may be helpful.

Help with mobility

Many people with myeloma find it difficult to get around properly. Some may be wheelchair users while others may need a variety of equipment such as sticks and zimmer frames to help them walk. If you have problems walking and are worried about falls, speak with your GP or hospital specialist who can refer you to a physiotherapist or occupational therapist.

People whose walking difficulties are permanent or long-term can get an NHS wheelchair on free loan.

Details of local wheelchair services are available from GPs, local health centres and the physiotherapy or occupational therapy departments of your local hospital. Wheelchairs can also be hired from the Red Cross (contact details in Further information and useful organisations on page 27). There are many disability associations that have information about more general travel issues for those with mobility problems. A good starting point is the organisation RADAR (contact details on page 27).

Benefits

Disability Living Allowance (DLA) may be claimed if you are under 65 years of age and have mobility problems or need some degree of care. The allowance is made up of two parts – care and mobility. These parts also have different rates, depending on the individual claim. DLA is non-means tested and therefore any savings and income you have do not affect the claim.

Sometimes a medical examination is necessary. If you are awarded DLA at the higher rate for mobility the vehicle you use will be exempt from road tax. It may also be possible to buy / hire a car through the Motability scheme if you are awarded this higher rate.

The Blue Badge scheme

If you have a permanent or substantial disability and / or are in receipt of higher rate DLA, you are eligible to apply for a Blue Badge for parking concessions. The Blue Badge scheme (this used to be called the Orange Badge scheme) allows certain groups of disabled people to park in parking restricted areas.

To apply for a Blue Badge in England and Wales, contact your local authority social services department. In Scotland, contact the local authority, and in Northern Ireland, the Department for Regional Development. There may be a small fee.

If you have a Blue Badge you may be able to get parking concessions when travelling in another country that also recognises the badge. However, each country continues to determine its own set of parking concessions for which the badge can be used.

The future

As research continues to provide a clearer understanding of the complex relationship between the myeloma cells, the bone cells and the bone marrow environment, it may be possible to find treatments that are able to disrupt these mechanisms.

This may lead to better ways of reducing or preventing myeloma bone disease and possibly also reduce myeloma cell growth and survival.

Examples of new treatments include:

- OPG / RANKL
- Targeted radiotherapy

Self-help checklist

- Report any new symptoms to your doctor
- Report pain to your doctor or nurse so that it can be treated
- Take pain-killing drugs as prescribed
- It is useful to keep a record of analgesic usage to show your doctor or nurse
- If your usual combination of pain-killers becomes less effective, contact your doctor or nurse
- If you are on oral bisphosphonates, such as Bonfos or Loron, take them as prescribed, avoiding food an hour before and after you take them
- Try and take regular gentle exercise - talk to your doctor if you are worried about the risks of exercise or are considering trying something new
- Check to see if you are entitled to any benefits or financial assistance because of mobility problems
- If you are having problems walking around and carrying out your usual daily activities talk to your GP. You may be able to improve your mobility with help and support from specialist healthcare professionals
- If you are seeing an orthopaedic surgeon or radiotherapist make sure that they are liaising with your myeloma specialist and keeping each other informed of changes in your condition or treatment

Medical terms explained

Anaemia: A below-normal number of red blood cells in the blood. This reduces the ability of the blood to supply oxygen to the body, causing fatigue and weakness.

DNA: Or deoxyribonucleic acid, is the hereditary material in humans and almost all other organisms.

Hypercalcaemia: A higher-than-normal level of calcium in the blood. This condition can cause a number of symptoms, including loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness, and confusion. Common in myeloma patients and usually resulting from bone destruction with release of calcium into the blood stream. Often associated with reduced kidney function as calcium can be toxic to the kidneys. For this reason, hypercalcaemia is usually treated on an emergency basis using IV fluids combined with drugs to reduce bone destruction together with direct treatment for the myeloma.

Immunoglobulins: Also known as antibodies, immunoglobulins are proteins found in the blood which are produced by cells of the immune systems, called plasma cells. Their function is to bind to substances in the body that are recognised as foreign antigens found on the surface of bacteria and viruses.

Interventional radiologist: Interventional radiologists specialise in invasive procedures; they can biopsy internal organs, open blocked arteries and veins, drain abscesses and cysts and treat many other conditions and / or disorders. Interventional radiologists use the results of many of the radiologic procedures. In many interventional radiology procedures, patients are treated on an outpatient basis and are back to their normal routines quickly.

Lytic lesions: The damaged area of a bone that shows up as a dark spot on an X-ray when enough of the healthy bone in any one area is eaten away. Lytic lesions look like holes in the bone and are evidence that the bone is being weakened.

MGUS: Monoclonal Gammopathy of Uncertain Significance (MGUS) is a premalignant disorder characterised by the accumulation of plasma cells within the bone marrow and the presence of a monoclonal protein spike on electrophoresis. The feature that distinguishes it from myeloma is the lack of end organ damage. What this means is that there is no lytic bone lesions, renal damage or anaemia. The condition is stable, but after 10 years of follow-up approximately 20% of patients will have progressed to clinical myeloma.

Non-secretory myeloma: Non-secretory myeloma is characterised by the absence of a paraprotein in both serum (fluid component of blood) and urine. It occurs in approximately 2% of all myeloma patients.

Osteosclerotic myeloma: A rare condition in myeloma where there is excessive bone growth rather than bone breakdown.

Phase III: Are studies to compare a new / novel treatment with the best current standard treatment. Such studies are randomised (i.e. a computer is used to choose which patients receive which treatment).

Plasma cells: Special white blood cells that produce antibodies. The malignant cell in myeloma. Normal plasma cells produce antibodies to fight infection. In myeloma, malignant plasma cells produce large amounts of abnormal antibodies that lack the capability to fight infection. The abnormal antibodies are the monoclonal protein, or M protein. Plasma cells also produce other chemicals that can cause anaemia, as well as kidney and nerve damage.

Smouldering myeloma: In this condition there is minimal end organ damage but the level of plasma cells in the bone marrow and the paraprotein level are not stable and are associated with inexorable progression to myeloma. Conventionally, treatment is withheld until there is significant evidence of disease progression.

Solitary plasmacytoma of bone: A collection of myeloma plasma cells found in a single location, either in the bone marrow or soft tissue.

Further information and useful organisations

General information and advice

Cancerbackup

www.cancerbackup.org.uk

0808 800 1234 (Monday-Friday, 9am-8pm)

Cancerbackup helpline workers are trained oncology nurses who can provide information and support to people affected by cancer. Also publishes a wide range of patient information.

Leukaemia CARE

www.leukaemiacare.org.uk

0800 169 6680 (24hrs)

Its Care Line is staffed 24 hours a day, 7 days a week by trained volunteers who offer befriending, support and information about leukaemia and other blood disorders.

Leukaemia CARE also offers discretionary financial assistance and caravan holidays in the UK.

Leukaemia Research

www.lrf.org.uk

0207 405 0101 (Monday-Friday, 9am-5pm)

Leukaemia Research funds research into leukaemia and related blood disorders.

It publishes patient information about leukaemia and other blood disorders, including myeloma.

Macmillan Cancer Support

www.macmillan.org.uk

Its CancerLine 0808 808 2020 (Monday-Friday, 9am-6pm)

The CancerLine is staffed by specialist advisors who provide information, practical and emotional support to those affected by cancer. Macmillan's other services include Macmillan nurses and patient grants, as well as a network of over 750 cancer self-help groups.

Emotional support

British Association for Counselling and Psychotherapy (BACP)

www.bacp.co.uk

0870 443 5252 (Monday-Friday, 8.45am-5pm)

BACP provides information about counselling and can give you a list of local registered counsellors.

Depression Alliance

www.depressionalliance.org

0845 123 2320 (Information pack request line)

Provides information, support and understanding for those affected by depression and coordinates a network of self-help groups throughout the UK. Depression Alliance also produces a wide range of publications covering various aspects of depression.

Relate

www.relate.org.uk

0845 130 4016 (Monday-Friday, 9am-5pm)

Relate offers a confidential counselling service for couples or individuals experiencing difficulties in their relationship. Relate provides support face-to-face, by phone and through its website.

Mobility, medical and palliative care

Blue Badge Scheme

www.dft.gov.uk (Department for Transport website)

The Blue Badge Scheme provides a national arrangement of on-street parking concessions enabling people with severe walking difficulties who travel, either as drivers or passengers, to park close to their destinations. To apply for a badge, contact the social services department (or in Scotland the social work department) of your local authority or council.

DIAL

www.dialuk.info

01302 310 123

DIAL provides information and advice on all aspects of living with a disability, including transport, mobility and equipment.

NHS Direct / NHS24

www.nhsdirect.nhs.uk

In England, Northern Ireland and Wales call NHS Direct on 0845 46 47

In Scotland call NHS24 on 08454 24 24 24

Staffed by trained medical professionals, it provides 24-hour access to information about all aspects of health and healthcare.

Pain Concern

www.painconcern.org.uk

01620 822572 (Weekdays 9am-5pm and Fridays 6.30-7.30pm)

Pain Concern provides a range of information about managing pain and self-help. Its helpline offers information, support and a listening ear.

Red Cross

www.redcross.org.uk

0870 170 7000

The Medical Equipment Service has a wide range of products and equipment available for short-term loan. The Home from Hospital Service provides short-term practical assistance and support to help people settle back into their own homes. A Transport and Escort Service offers help to people who cannot get about easily or use ordinary transport.

Royal Association for Disability and Rehabilitation (RADAR)

www.radar.org.uk

0207 250 3222

RADAR is a national organisation for disabled people. It provides information and advice on all aspects of living with a disability, including transport and mobility. It runs the National Key Scheme, which offers disabled people access to 7,000 locked public toilets around the country.

Complementary therapy

Institute for Complementary Medicine

www.icmedicine.co.uk

0207 237 5165 (Monday-Friday, 10am-3.30pm)

Provides information about registered practitioners of various complementary therapies.

Penny Brohn Cancer Care

www.pennybrohncancercare.org

0845 123 2310 (Monday-Friday, 9.30am-5pm)

The Bristol centre offers complementary cancer care to work alongside medical treatment. Its helpline offers emotional support and information about complementary therapists and services in your area.

With Myeloma UK you can...

Call our Myeloma Infoline on 0800 980 3332

You will immediately access information and support relating to all aspects of myeloma. Your call will be answered in confidence by Myeloma Information Nurse Specialists who are supported by medical and scientific advisors. Lines are open Monday to Friday, 9am to 5pm, and are free to phone from anywhere in the UK. From outside the UK call +44 131 557 3332 (charged at normal rate).

Contact us by email

If you have a specific question about any aspect of myeloma, treatment or living with myeloma, you can also contact our Myeloma Information Nurse Specialists by email at askthenurse@myeloma.org.uk

Order our free patient information

Myeloma UK has a range of Essential Guides, Infoguides and Infosheets which give information on myeloma and related disorders, providing details of treatment options and disease management. You will find a list of the information available from us at the back of this Infoguide.

Attend our Patient and Family Myeloma Infodays

These are full-day meetings, where you can learn about the latest in the treatment and management of myeloma from a panel of experts. They are also a valuable opportunity to meet others affected by myeloma.

Subscribe to *Myeloma Matters*

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

Visit our website - www.myeloma.org.uk

Developed to provide immediate, 24-hour access to information about myeloma and related disorders to individuals affected by the disease and to the people caring for them.

We need your help

Each year, Myeloma UK sends Infoguides and Infosheets to nearly 10,000 patients and their families, and helps thousands more through providing services such as the Myeloma Infoline and Patient and Family Myeloma Infodays.

That is why we need your help

We depend on the support and generous donations from people like you to provide these important services which are available free to myeloma patients, their families and carers.

Will you help us to help others?

- £5 will pay for an Infopack to be sent to help one more patient
- £20 will allow one of our highly trained Myeloma Information Nurse Specialists to help two callers on our Myeloma Infoline
- £50 will pay for a family of three to attend a Myeloma Infoday
- £250 will pay for 2,000 patient information Infosheets

Simply choose the amount that is right for you, or, if you prefer, choose an amount of your own. To donate you can either post your donation (by cheque or CAF), use your credit card to donate by telephone or use the Myeloma UK website www.myeloma.org.uk

We can make your money go further if you are a UK taxpayer. If you pay tax at the basic rate, we can claim money back for every pound you donate.

For example, if you donate £10 then we are able to claim back £2.80, (£2.50 after April 2008) so your donation becomes £12.80 (£12.50 after April 2008).

This extra comes from the taxman and doesn't cost you anything. This process is called Gift Aid.

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Other information available from Myeloma UK

Myeloma Infopack

The Myeloma Infopack contains general information about myeloma, treatment options and disease management. It also has information about Myeloma UK and the range of services available to those affected by myeloma.

Booklets

Myeloma – Your Essential Guide

Living with Myeloma - Your Essential Guide

Infoguides

Balloon Kyphoplasty

Chemotherapy

Clinical Studies

High-Dose Therapy and Stem Cell Transplantation

MRC Myeloma IX

Percutaneous Vertebroplasty

Revlimid

Serum Free Light Chain Assays

Thalidomide

Velcade

Infosheets

Infosheet topics include:

Diet and Nutrition; Erythropoietin; Fatigue; Growth Factors; Managing Your Finances (including Benefits); Mouthcare; Pain; Peripheral Neuropathy; Plasmapheresis; Radiotherapy; Steroids; Support Groups; The Kidney; Travel Insurance; Travelling.

Leaflets

Myeloma – An Introduction

There are a number of conditions closely associated with myeloma. Myeloma UK has information available on AL amyloidosis, Waldenström's macroglobulinaemia and MGUS

To order these free publications please contact Myeloma UK.

Myeloma Infoline: 0800 980 3332 (freephone number) or 0131 557 3332

www.myeloma.org.uk email: myelomauk@myeloma.org.uk

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All myeloma UK's publications are reviewed by patients and healthcare professionals prior to publication.

Myeloma Infoline 0800 980 3332

www.myeloma.org.uk



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

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