Patient Guide for

Myeloma Bone Disease and Bisphosphonates

English

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MYELOMA PATIENTS EUROPE

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Patient Guide for Myeloma Bone Disease and Bisphosphonates

Contents

Introduction

This brochure is written for myeloma patients, their families and friends. It provides information on why myeloma bone disease occurs, 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 Medical terms explained at the back of the brochure.

This brochure aims to:

- Help you understand more about myeloma bone disease
- Help you understand more about bisphosphonate treatment
- Provide answers to questions you may have about myeloma bone disease
- Help you make informed treatment decisions

Basic information for this brochure was taken from the brochure „Myeloma Bone Disesase and Bisphosphonates“, Myeloma Infoguide Series, Myeloma UK.

Be informed!
The information in this brochure 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.

What is myeloma bone disease?

Myeloma bone disease is the most common and often the most debilitating feature of myeloma and bone pain is a very common symptom. Between 70 – 80% of patients have evidence of myeloma bone disease at the time of diagnosis and most patients will get myeloma bone disease at some point.

Myeloma 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 myeloma bone disease varies considerably from patient to patient. 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).

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 often result in loss of height and / or curvature of the spine as well as pain.

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

1 Lytic lesions

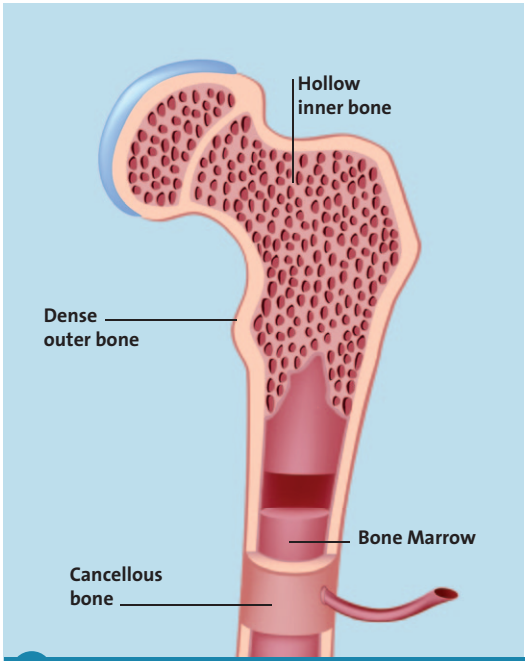
Normal activity of bone cells

Bones are made up of a dense 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.

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 cell types which play a key role in the normal activity of bones – these are:

- Osteoblasts (cells which form new bone)
- Osteoclasts (cells which break down old bone)

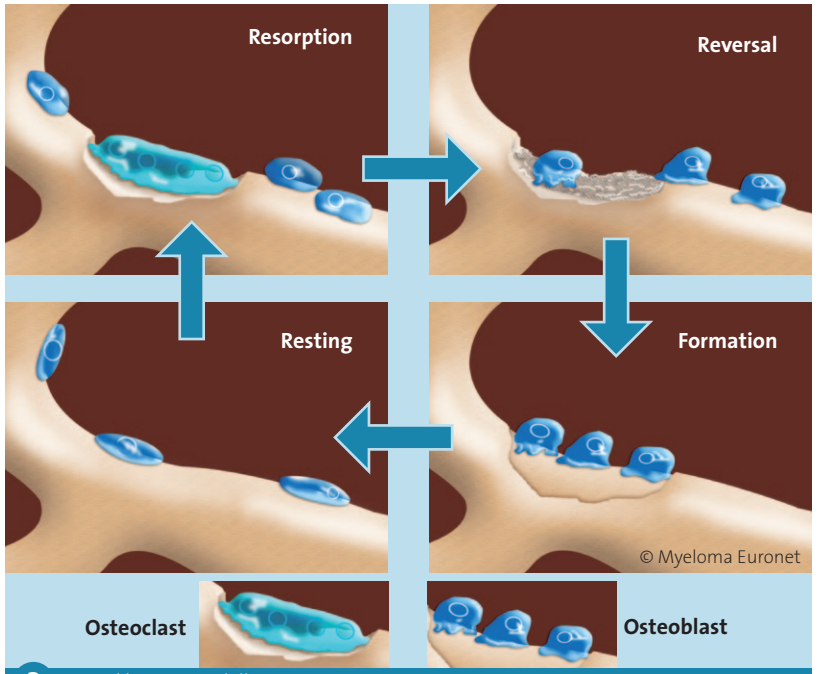


2 Bone structure

The cycle of bone breakdown and formation keeps the bone in a continual state of renewal. 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 formation 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 a net loss of bone.



3 Normal bone remodelling

Bone cell activity in myeloma

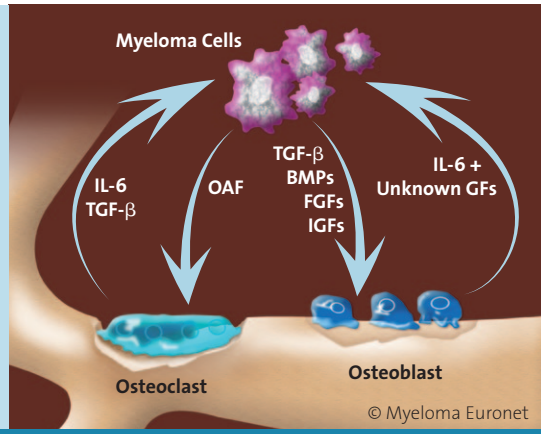
Myeloma cells can cause bones to breakdown by producing signals and substances known as cytokines and growth factors that activate bone breakdown but which inhibit new bone formation.

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

In addition, the osteoclasts produce factors that stimulate the myeloma cells to grow, especially Interleukin 6 (IL-6). This results in a vicious cycle of dependency between the myeloma and bone cells which occurs in what is called the bone marrow micro-environment. It is these processes that result in a net loss of bone and lytic lesions in myeloma.

Cytokines involved in bone renewal process:

IL – 6: Interleukin 6
OAF: Osteoclast activating factor
TGF-ß: Transforming growth factor beta
IGFs: Insulin-like growth factors
FGFs: Fibroblast growth factors
BMPs: Bone morphogenic proteins



4 Bone remodelling

Tests and investigations to detect and monitor myeloma bone disease

Myeloma bone disease is the most common presenting symptom at diagnosis. Therefore bone tests will normally be done alongside blood, urine and bone marrow tests to help make the diagnosis and to decide on the need for treatment. Some of these tests are repeated during treatment and follow-up.

Common tests and investigations to detect and monitor myeloma bone disease include:

X-ray

Standard X-rays are routinely 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 does not show up any areas of damage, but myeloma bone disease is suspected, other imaging techniques may be used. Such techniques can also provide more detail of a particular area if required.

Be informed!
Many patients are afraid that X-ray will cause more cancer activities. For myeloma patients it is an important tool to check the bone status.

Computerised Tomography (CT) scans

CT scans can be used when a detailed evaluation of a small area of suspected bone damage is required or for detecting myeloma that may exist outside of the bones, for example in soft tissue. They can also be used to pinpoint the exact area where radiotherapy treatment is to be given. Whole-body CT of the skeleton (Osteo-CT) is the most sensitive technique to detect lytic bone lesions.

Magnetic Resonance Imaging (MRI)

MRI is the best technique for the imaging of the spine and is preferred for detection of spinal cord compression. MRI may be used if X-rays are inconclusive or more detailed testing is needed. MRI uses computerised measurements of radio waves, which enable a detailed view of the bone marrow. MRI does not involve radiation. With MRI the manifestation of myeloma in soft tissue can be detected very good.

The spine showing bone marrow within the vertebrae and areas of myeloma bone disease

Normal marrow is bright. Abnormal areas are dark.

5 Image from MRI scan

Fluoro-deoxyglucose positron emission tomography (FDG / PET scanning)

Whole body FDG / PET is a relatively new, albeit a less routine scanning technique used to diagnose myeloma bone disease. This procedure involves a low-dose radioactive drug which accumulates in areas where there is active myeloma lesions within the bone.

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 because of these fractures that myeloma may often be first diagnosed.

Lytic lesions

In addition to osteopenia, myeloma can also cause lytic lesions or 'holes' which are most commonly found in the skull, spine, pelvis, ribs and the long bones of the arms and legs.

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.

Spinal cord compression

This is a complication that sometimes occurs when an area of myeloma in the spine causes 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 moving the bowels often occur.

Be aware!
Spinal 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.

Collapsed vertebrae / kyphosis / height loss

Where myeloma bone disease has been more aggressive or prolonged, some bones can develop holes. If this happens in the bones of the spine, it can result in a more dramatic collapse of the vertebrae than you would expect with just the presence of lytic lesions which may cause stress fractures only. Sometimes the collapse changes the shape of the spine (kyphosis) and causes loss of height.

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 most often presents at the time of diagnosis, is less common once treatment has started, but may be present at relapse.

Pain

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

The intensity of the pain experienced varies from patient to patient. It is usually aggravated by movement and relieved by lying down. Pain can progressively 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 most cases, myeloma bone disease is likely to be an ongoing issue. However, there are treatments available that can slow down its activity, alleviate its symptoms and sometimes correct the complications that occur.

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

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

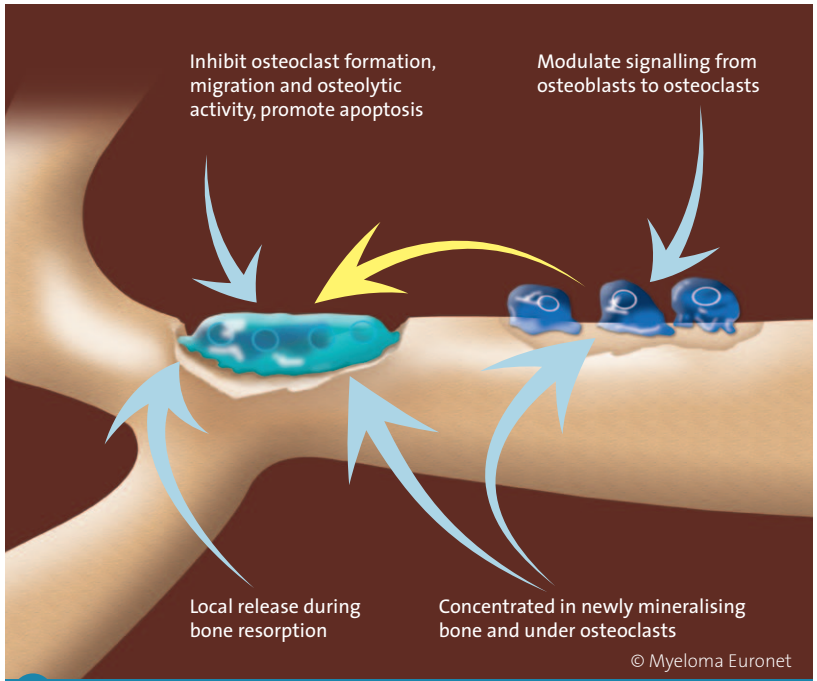
Bisphosphonates

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 ongoing osteolytic cycle and therefore the increased bone breakdown.

Bisphosphonates therefore have several potential beneficial effects including:

- Preventing / slowing down further bone breakdown
- Reducing bone pain and the need for painkillers
- Preventing and correcting hypercalcaemia
- Reducing the need for radiotherapy

- Reducing the likelihood of pathological fractures due to myeloma bone disease
- Improving quality of life by decreasing pain and maintaining mobility
- Improving the chances of healing and recovery of strength of bone



6 Mechanisms of action of bisphosphonates

What are the different types of bisphosphonates?

There are three bisphosphonates licensed for use in Europe to treat myeloma bone disease.

These are shown in the following overview together with their method of administration.

The brand names differ from country to country, the overview lists some common examples. Please ask your doctor about specific brand names for your country.

Sodium clodronate	Bonefos® Loron® Ostac®	• Oral tablets, taken at least twice per day • best to be taken with a glass of tap water, without eating or drinking before • at least one hour before meals, drinks (without water) or medications • not to be taken together with milk, meals or medications, which include calcium
Disodium pamidronate	Pamifos®	• iv infusion over 2 – 4 hours every month – the slowlier the better
Zoledronic acid	Zometa®	• iv infusion over 15 – 30 minutes every month

What are the potential 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, impaired kidney function and bone pain.

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 usually successfully 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 painkillers such as paracetamol.

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

Dehydration – the increased resolution of the bone calcium in the blood leads to increased calcium excretion through the kidneys. In consequence, the amount of urine and body threatens to dry up. At the same time on the kidneys are damaged.

Impaired kidney function is an important potential side-effect. All three bisphosphonates can potentially harm kidney function. The symptoms can be: loss of appetite, fatigue, muscle weakness, restlessness, concentration difficulties, confusion, obstipation, thirst, increased urine production, dizziness and vomiting. 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 using 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 2,5 litres of water a day. As mentioned, bisphosphonates, especially the intravenous versions, can increase the risk of impaired kidney function. Therefore, bisphosphonates should be used with caution in patients who have **already** impaired kidney function.

Osteonecrosis of the jaw – pain and poor healing in the jaw, particularly after tooth extraction, have been reported in some cases. As a precaution, patients taking bisphosphonates should have a visit by a dentist before starting bisphosphonates. They should have regular dental check-ups and inform their doctor before any planned oral surgery/tooth extractions. See information on side 38/39 “Councilors dental service”.

Who should and who shouldn’t receive bisphosphonates?

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

- The long-term bisphosphonates for all myeloma patients requiring treatment for their myeloma, whether or not bone lesions are evident
- Bisphosphonates should be used with caution in patients who have evidence of renal impairment
- **Patients who have allergic reactions or who have a contraindication to bisphosphonate treatment should not take them**

Which bisphosphonate should I take?

Although the different types of bisphosphonates have different potencies, all bisphosphonates approved for myeloma bone disease are effective for this indication.

Data from a recent clinical study has shown if zoledronic acid is given via intravenous infusion it is more effective than oral clodronate to absorbe when taken in conjunction with their myeloma treatment. This is the only study to date comparing an oral versus an IV bis-phosphonate.

The study involved newly diagnosed patients who were given either zoledronic acid or sodium clodronate in addition to their myeloma treatment. At the end of the study the results showed that zoledronic acid had the following benefits:

- Patients experienced fewer fractures, lytic lesions and other symptoms of myeloma bone disease
- Duration of progression free survival was greater
- Duration of overall survival was greater

Zoledronic acid is superior to clodronate.

When discussing the different bisphosphonates, you and your doctor may consider that an alternative one is more appropriate according to your situation and preferences. It is important to have this conversation so that the right choice is made.

If you have any questions or queries in relation to the above, please contact your doctor.

Do bisphosphonates have an anti-myeloma effect?

It has been suspected for some time that certain bisphosphonates may have an anti-myeloma effect. Meanwhile this has been proven through data from a clinical study.

In the study, zoledronic acid was shown to have certain benefits over sodium clodronate. The study participants included patients with and without myeloma bone disease. Improved duration of progression free survival and overall survival was seen in patients treated with zoledronic acid who did not have myeloma bone disease, as well as patients with myeloma bone disease.

This suggests that zoledronic acid may have an anti-myeloma effect for newly diagnosed myeloma patients, as well as preventing myeloma bone disease.

More research into the anti-myeloma effect of bisphosphonates is required. This study found a potential survival benefit for newly diagnosed myeloma patients. Therefore, it is not known if the same effects will be observed in other myeloma patient groups.

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 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 for patients with localised severe pain. Radiotherapy kills the myeloma cells in the bone, which in turn reduces bone pain. Pain relief from radiotherapy is sometimes more rapid than with drug treatment 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.

Painkilling drugs (analgesics)

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

- Painkillers for mild pain, e.g. paracetamol
- Painkillers for moderate pain, e.g. dihydrocodeine
- Painkillers for severe pain, e.g. morphine and fentanyl
- Painkillers for nerve-type pain (peripheral neuropathy), e.g. gabapentin and amytriptyline

When taking painkillers, it is important for your doctor to find the one that works best for you through a trial and error approach, as no two patients are alike. Painkillers, like other treatments, can cause side-effects and this differs from patient to patient.

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

Painkillers 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 and diclofenac are common painkillers, but should ideally be avoided in myeloma patients, particularly those with kidney damage.

It is always best to check with your doctor regarding the best painkiller to use.

Surgical interventions

Surgery may be appropriate 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

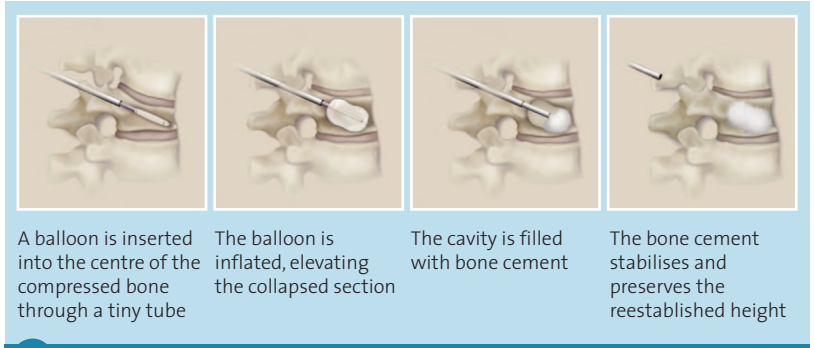
Two relatively new surgical procedures known as Percutaneous vertebroplasty and Balloon kyphoplasty have been developed to treat fractures of the spine. These procedures are normally performed

by a specialist spinal surgeon or an interventional radiologist and can be done under either local or general anaesthetic.

Percutaneous vertebroplasty 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 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 is a similar procedure to Percutaneous vertebroplasty which in addition to stabilizing aims to reshape and restore the height of the damaged vertebra.

Balloon kyphoplasty is achieved by inserting a balloon into the fractured vertebra and inflating it before the cement is inserted (see Figure 7). This helps restore the vertebra to its original shape, 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

7 Balloon kyphoplasty

Patients who may benefit from Percutaneous vertebroplasty or Balloon kyphoplasty

Although similar, Percutaneous vertebroplasty and Balloon kyphoplasty are not interchangeable and are indicated for different clinical situations, therefore careful selection of patients who might benefit is important.

In general, more conservative treatments for back pain will usually be tried first, depending on the location of the pain, the type of vertebral compression fracture and the time elapsed since the fracture occurred.

In Germany guidelines recommend to consider an operative intervention after 3 weeks of conservative treatment without success. Each country has own guidelines with different recommendations. Please ask your doctor about your possibilities.

The following criteria would be applied to both procedures when selecting patients:

- 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 eligible 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 relatively new procedures, they are not yet available in every hospital although more and more radiologists are being trained to carry out these procedures every year and availability is improving all the time.

Recommendations are available from NICE (The National Institute for Health and Clinical Excellence) on the use of Percutaneous vertebroplasty and Balloon kyphoplasty. These are available on the NICE website – **www.nice.org.uk**

More information about Balloon kyphoplasty you will find on the website – **www.kyphon.com**

Non-medical treatments

There are many non-medical treatments 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 painkillers, called endorphins. They can be useful in treating specific areas of pain.
- **Hot and cold compression packs:** Hot water bottles and ice packs can be effective short-term pain relievers. It is best not to place them directly on the skin, and you may need to alternate between hot and cold.
- **Relaxation techniques:** Meditation, visualisation, relaxation or a combination of these can be helpful in relieving pain.
- **Positioning:** The way you sit or lie down can affect your pain. Move to get comfortable, use supportive pillows and ask for help from a family member 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 wellbeing. However, having myeloma may make exercise more difficult because of the effects of myeloma bone disease and also the side-effects of treatment, muscle weakness and fatigue.

To date there have been no studies to specifically 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, without the exercise causing injury and that exercise may be benificial.

The type of exercise that can be done will depend on the severity of your myeloma bone disease 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 taking part in 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

Some myeloma patients have mobility problems. Many may be wheelchair users while others may need a variety of equipment such as sticks and walking frames to help them walk. If you have problems walking and are worried about falls, speak with your doctor or nurse who can refer you to a physiotherapist or occupational therapist.

Myeloma patients whose walking difficulties are permanent or long-term may be eligible for a wheelchair. Details of local wheelchair services are available from local health centres and the physiotherapy or occupational therapy departments of your local hospital.

Ask your local patient organisation about their experiences!

There are many disability associations that have information about more general travel issues for those with mobility problems.

The future

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

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

An example of a new treatment approach is with denosumab which is currently the subject of clinical studies around the world. Denosumab is an antibody which binds specifically to a protein called RANKL that is critical for causing osteoclasts to break down bone.

Other new approaches are being tested which target not only the myeloma cells but also the bone marrow microenvironment.

Research for new bisphosphonates are also ongoing to determine an antimyeloma effect.

Much emphasis is also being placed on understanding the genetics of myeloma. It is hoped that this information may identify features that underlie myeloma bone disease that can be used to help predict a patient's response to treatment. It may also lead to the development of better treatments for myeloma bone disease.

Self-help checklist

- Report any new symptoms to your doctor
- Report pain to your doctor or nurse so that it can be treated
- Take painkilling drugs as prescribed
- It is useful to keep a record of analgesic usage to show your doctor or nurse
- If your usual combination of painkillers becomes less effective, contact your doctor or nurse
- If you are on oral bisphosphonates, such as Sodium clodronates, take them as prescribed, avoiding food an hour before and after you take them
- Try to take regular gentle exercise – talk to your doctor/ physiotherapist 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 doctor. 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 well informed of changes in your condition or treatment

Medical terms explained

- **Interventional Radiologist:** Interventional Radiologists specialise in invasive procedures that can biopsy internal organs, open blocked arteries and veins, drain abscesses and cysts and treat many other conditions and / or disorders. Interventional Radiologists are often involved in the treatment of myeloma bone disease. 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.
- **Osteonecrosis of the jaw (ONJ):** A condition in which the bones of the jaw do not heal properly causing ongoing, sometimes painful, complications. Make sure your dentist knows about myeloma and treatment with bisphosphonates.
- **Paraprotein:** An antibody-like protein produced by the abnormal plasma cell in myeloma. It is found in the blood and sometimes also in the urine. It is also called monoclonal protein, myeloma protein, M-spike, M-protein or M band.
- **Side-effects:** Problems that occur when treatment affects healthy cells. Common side-effects of standard cancer treatments are fatigue, nausea, vomiting, decreased blood cell counts, hair loss and mouth sores.

Additional Resources

- **American Cancer Society:**
  http://www.cancer.org
- **American Society for Blood and Marrow Transplantation (ASMBT):**
  http://www.asbmt.org
- **American Society for Apheresis (ASFA):**
  http://www.apheresis.org
- **Blood and Marrow Transplant Information Network (BMT InfoNet):**
  http://www.bmtinfonet.org
- **Cancerworld:**
  http://www.cancerworld.org
- **Center for International Blood and Marrow Transplant Research (CIBMTR):**
  http://www.cibmtr.org
- **ClinicalTrials.gov:**
  http://clinicaltrials.gov
- **European CanCer Organisation:**
  http://www.ecco-org.eu
- **European Cancer Patient Coalition:**
  http://www.ecpc-online.org
- **The European Group for Blood & Marrow Transplantation (EBMT):**
  http://www.ebmt.org
- **The European Myeloma Network:**
  http://www.myeloma-europe.org
- **International Myeloma Foundation:**
  http://myeloma.org
- **LeukemiaNet:**
  http://www.leukemia-net.org
- **Leukaemia & Blood Cancer New Zealand:**
  http://www.leukaemia.org.nz
- **Leukemia and Lymphoma Society:**
  http://www.leukemia-lymphoma.org
- **Leukemia Research Foundation:**
  http://www.leukemia-research.org
- **Lymphomainfo.net:**
  http://www.lymphomainfo.net
- **Lymphoma Coalition:**
  http://www.lymphomacoalition.org
- **Lymphoma Research Foundation:**
  http://www.lymphoma.org
- **Multiple Myeloma Research Foundation:**
  http://www.themmrf.org
- **Myeloma Patients Europe:**
  http://myelomapatientseurope.org
- **National Bone Marrow Transplant Link (NBMT Link):**
  http://www.nbmtlink.org
- **National Cancer Institute:**
  http://www.cancer.gov
- **National Marrow Donor Program:**
  http://www.marrow.org

About
Myeloma Euronet

Myeloma Euronet, a non-profit network organization of multiple myeloma patient groups, is an European initiative dedicated to raising the awareness of multiple myeloma, an increasingly common form of bone marrow cancer.

Myeloma Euronet was launched at the 10th Congress of the European Hematology Association (EHA) in Stockholm on 3 June 2005. It is an international non-profit association (Association Internationale sans but lucratif, AISBL) registered in Belgium.

Myeloma Euronet's Secretariat is located in Ruesselsheim, Germany:
Myeloma Euronet
c/o Anita Waldmann
Falltorweg 6
65428 Ruesselsheim / Germany
info@myeloma-euronet.org

Myeloma Euronet has members in 23 European countries and is a member of the:

- European Cancer Patient Coalition (ECPC) www.ecpc-online.org
- European CanCer Organisation (ECCO) www.ecco-org.eu
- International Lymphoma Coalition (ILC) www.lymphomacoalition.org
- European Organisation for Rare Diseases (EURORDIS) www.eurordis.org

Myeloma Euronet is working in the Patient Advisory Committees of the:

- European Hematology Association (EHA) Scientific Working Group "Quality of Life & Symptoms" www.ehaweb.org
- European Society for Medical Oncology (ESMO) www.esmo.org
- European Group for Blood & Marrow Transplantation (EBMT) www.ebmt.org
- European Medicines Agency (EMA) www.ema.europa.eu

More information about Myeloma Euronet can be found at our multilingual, award-winning Web site at www.myeloma-euronet.org. This Website is available in the following languages: Arabic (in part), Czech, English, French, German, Greek, Italian, Polish, Portuguese, Romanian, Russian, Spanish and Turkish. The Web site also provides a wealth of information about myeloma, useful links to other support organisations, a list of events, a quiz, surveys and many other useful resources.

Myeloma Euronet provides information on the diagnosis, treatment and care of persons living with multiple myeloma and supports its member organisations in the fulfillment of their mission. Myeloma Euronet also advocates, independently and in collaboration with organisations with similar objectives, on behalf of those affected by multiple myeloma.

October 2011 Myeloma Euronet (ME) and European Myeloma Platform (EMP) merged to become Myeloma Patients Europe (MPE).

The goals of Myeloma Patients Europe are also to:

- Advocate the cause of myeloma among EU health care policy makers and share best practice in shaping appropriate policies at the European level
- Raise European awareness of multiple myeloma amongst relevant stakeholders and the public
- Provide information on appropriate diagnosis, treatment, care and support for myeloma patients and their families
- Build partnerships among members of Myeloma Euronet in order to share experience and expertise
- Encourage the growth of new multiple myeloma patient groups throughout Europe, especially in cities and countries where they are not found currently.

www.myelomapatientseurope.org

Drinking Schedule

(After consultation with your doctor)

Tips and information (recommendation for daily practice):

For you as plasmacytoma/multiple myeloma (PMM) patient, ample hydration is one of the most important measures you can take yourself. The following information lists some recommendations which amounts you should drink over the course of the day:

Time	Beverage	Amount in Litres
before breakfast	1 glass of water	0.2
with the breakfast	1 small glass of juice and 1 cup of coffee/tea	0.4
during the forenoon, between meals	2 glasses of mineral water or juice spritzer or buttermilk	0.4
with the lunch	1 cup of vegetable stock 1 glass of mineral water or vegetable juice spritzer	0.2 0.2 0.2
during the afternoon, between meals	2 cups of coffee/tea	0.4
with the dinner	2 cups of fruit or herbal tea	0.4
before bedtime	1 glass of mineral water or fruit spritzer	0.2
All in All		**2.6**

Tips and information:

- A glass of water in the morning activates the bowels and thus stimulates digestion as well.
- Fruit and vitamin juices (pay attention to the Ca++ content) are valuable beverages, since they provide important vitamins and mineral nutrients.
- Take only fruit juices without additional sugar.
- Mix fruit juices with water 1 : 1 to get a spritzer which quenches your thirst even better.
- Mineral water is an excellent thirst quencher. Moreover, it contains important mineral nutrients and is calorie-free.
- Sugar-free coffee and black tea are likewise suitable beverages (2 – 3 cups per day).
- Do not drink water or other beverages icy-cold; this will often quench thirst only briefly and may cause gastric problems.
- Sugared beverages such as lemonade, coke, fruit nectars, fruit juice soft drinks and alcoholic drinks have much energy (calories) and are thus not recommendable as thirst quenchers.
- Before each meal, drink 1 big glass of mineral water. This supports hydration and is indispensable for the flushing of your kidneys.
- Please get informed about the calcium content of your regional tab water.

Transfer/councel before Bisphosphonate-therapy

Patients dates:

date signature

Basic disease:

☐ Multiple Myeloma/Plasmacytoma
☐ Breast cancer
☐ Prostata cancer
☐ Other tumor _____
☐ Osteoporosis
☐ Other, which _____

Indication:

☐ Osmotic metastastis
☐ oligometast. ☐ multiple
☐ Profilaxis, without osseatic metast.
☐ others _____

Special information:

Urgency of therapy ☐ high ☐ medium ☐ low
Indication of therapy ☐ cure ☐ palliative
Since when bisphosphonate-therapy is applicated _____

Bisphosphonate:

Which one _____
Kind of application ☐ intravenous ☐ oral
Dosage _____ intervals _____
Duration of application, planned _____
Change of the medication ☐ done, when _____
☐ formerly _____ ☐ since _____
☐ planned, when _____ ☐ provided, which one _____

Prospective oncological therapy:

☐ Chemotherapy: regime _____
☐ Radiotherapy, head/throat: dosis _____
fractionation _____
☐ Hormone therapy, which one _____
☐ Immuna- or antibody therapy, which one _____
☐ Cortisone, how long _____
☐ Other relevant medication _____

Dental status

(to be filled in by a dentist or oral and maxillofacial surgeon)

☐ upcoming dental extractions, if necessary, when _____ ☐ therapy done
☐ necrotizing ulcerative Periodontitis (formerly acute marginal P.) ☐ therapy done
☐ chronic (including aggressive) Periodontitis (formerly chronic marginal P.) ☐ therapy done
☐ apical Periodontitis ☐ therapy done
☐ carious lesions ☐ therapy done
☐ Implants ☐ Periimplantitis ☐ therapy done
☐ mucosa-supported dentures ☐ pressure points ☐ therapy done
☐ prosthetic resupply necessary, if so, when? _____ ☐ therapy done
☐ other bacterial contamination, which? _____ ☐ therapy done

Recommended recall intervals
☐ 3 months ☐ 6 months ☐ 12 months

_____
date, signature

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provided by Myeloma Euronet

Thank you for your support!

MYELOMA EURONET

Myeloma Euronet – The voice of myeloma patients in Europe