Myeloma Australia

LIVING WELL INFOSHEET

Managing myeloma bone disease

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Things to remember

- Bone disease and bone pain are the most common symptoms of myeloma.
- In myeloma, the balance of breaking down old bone and building new healthy bone is disrupted, and this can result in thinner, weaker bones which can break more easily.
- There are many different types of scans used to diagnose and monitor bone disease. Your treating team will recommend the type of scan or scans best suited to your needs.
- While existing bone damage from myeloma can't be undone, new symptoms can be prevented by using bisphosphonate therapy alongside your other treatments for myeloma.
- Bisphosphonates are generally well-tolerated and side effects are usually mild.
- Sometimes, a type of medicine called a monoclonal antibody is used to treat myeloma bone disease instead of bisphosphonates. Your treating team will let you know if this is an option for you.
- Healthy eating and exercise can also help you to maintain bone health.
- Your treating team can help with a pain management plan so you can enjoy the best possible quality of life.

If you're reading a printed version of this infosheet, we've used a magnifying glass symbol throughout to let you know where you can search for more information in the **'Learn more'** section at the end of this infosheet.

Myeloma bone disease

Myeloma bone disease, which is sometimes shortened to MBD, and bone pain are the most common symptoms of myeloma, affecting about 80% of people with the condition. In fact, myeloma is often first diagnosed when bone pain is being investigated.

Many people find that bone disease and the pain it causes is one of the most challenging parts of living with myeloma. It helps to know that there are treatments that help manage bone disease and its symptoms, including bone pain. There are also simple things you can do to encourage bone health, which we've included on page 9 of this infosheet.

What causes myeloma bone disease?

Healthy human bones are maintained by a fine balance between the:

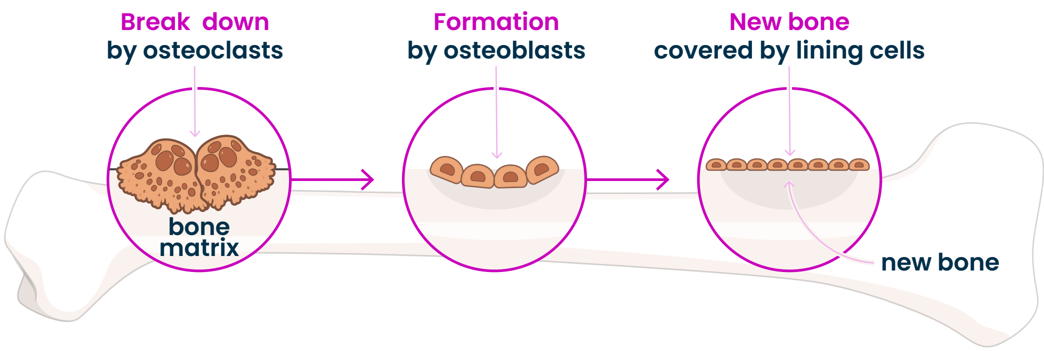
- breakdown of old bone by cells called *osteoclasts*
- building of new bone by cells called *osteoblasts.*

This cycle usually keeps bones in an ongoing state of renewal, which is called bone remodelling.

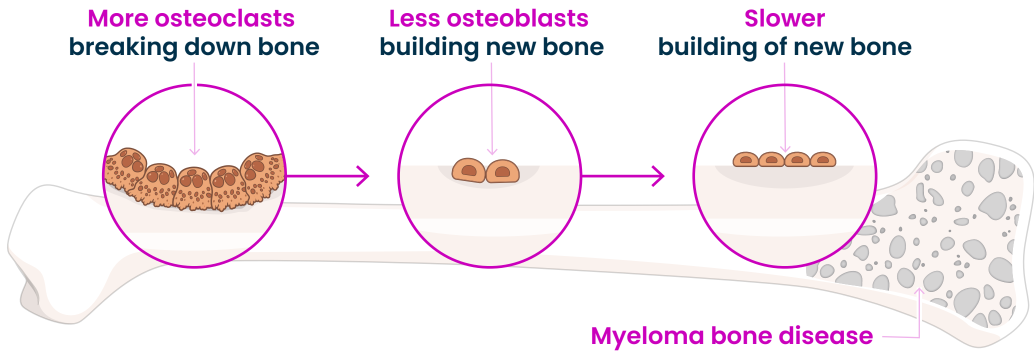
In myeloma, this balance can be disrupted. Myeloma cells send signals to the osteoclasts, causing them to *increase* bone breakdown. At the same time, myeloma cells *reduce* the activity of osteoblasts, which slows the building of new bone.

Healthy bone remodelling compared with myeloma bone disease

Healthy bone remodelling



Myeloma bone disease



What happens in myeloma bone disease?

The imbalance of bone breakdown and building in myeloma can lead to:

- **osteoporosis or osteopenia** — where your bones become thinner and weaker and develop weak spots, causing them to break more easily
- **lytic lesions** — holes in your bones, which also cause them to break more easily
- **pathological fractures** — where your bones break even from a small amount of pressure
- **compression or crush fracture** — when one or more bones in your spine (vertebrae) collapse, causing a loss of height or hunched posture
- **hypercalcaemia** — where bone breakdown causes calcium to be released into the blood too quickly
- **bone pain** — which is the most common symptom of myeloma bone disease
- **neurological complications** — when nerves in your spinal cord are compressed due to a fracture or myeloma tumour, which can cause pain, weakness, tingling, loss of sensation, or problems passing urine or using your bowels.

The bones most commonly affected by myeloma bone disease are the ones in your spine, pelvis, ribs and skull — which are sometimes called the axial skeleton. The upper ends of the long bones in your arms and legs can also be affected, but the bones in your hands and feet are rarely affected as they have very little bone marrow space.

You will usually experience ongoing pain where myeloma had caused bone damage. This pain may be made worse with movement. Sudden or severe pain may be a sign of fracture.

Always let your treating team know if you experience new pain, and get immediate medical attention for pain that comes on suddenly or is severe.

How is myeloma bone disease diagnosed and monitored?

For many people, bone disease is one of the first signs of myeloma, and so you are likely to have scans (also known as 'imaging') to confirm your diagnosis, along with blood, urine and bone marrow tests. Usually, you will have more scans done after treatment, or if you have new or increasing areas of bone pain.

There are many different types of scans used to diagnose and monitor myeloma bone disease. Your treating team will recommend the type of scan or scans they think will be best for you, depending on the location and type of symptoms you have.

Not all scans are available in every centre, and some are not covered by Medicare. Your treating team will consider all of this when recommending the scan or scans you need.

Scans and tests that your treating team may recommend include:

- **Whole-body low-dose CT (WBLDCT)** is a modified type of computerised tomography (CT) scan that uses a lower dose of radiation than conventional CT scans and can identify myeloma-related bone changes and bone damage called *lytic lesions*.
- **Magnetic resonance imaging (MRI)** uses a combination of radio waves, a powerful magnetic field and a computer to provide detailed images of your bones and soft tissue, such as the spine and brain. An MRI can show small bone lesions, spinal cord compression, and soft tissue problems. It can also show the amount and pattern of myeloma cells in your bone marrow. An MRI does not use any radiation.
- **Positron emission tomography-computed tomography (PET/CT)** scans involve having a radioactive medicine called fluoro-deoxy-glucose injected into a vein to highlight areas of rapid cell growth such as tumours.
- If any of these scans show osteoporosis, your treating team may also recommend a **bone density test**. This uses a plain x-ray of your hips and spine to work out your bone density and risk of fracture.
- **Your treating team will also use blood tests** to monitor calcium levels in your blood, which can be a sign of myeloma bone breakdown.

If you have non-secretory myeloma, where there is no detectable paraprotein in your blood or urine, your team may rely on scans alone to monitor your myeloma.

How is myeloma bone disease treated?

Myeloma bone disease is most commonly treated with a type of medicine called a bisphosphonate.

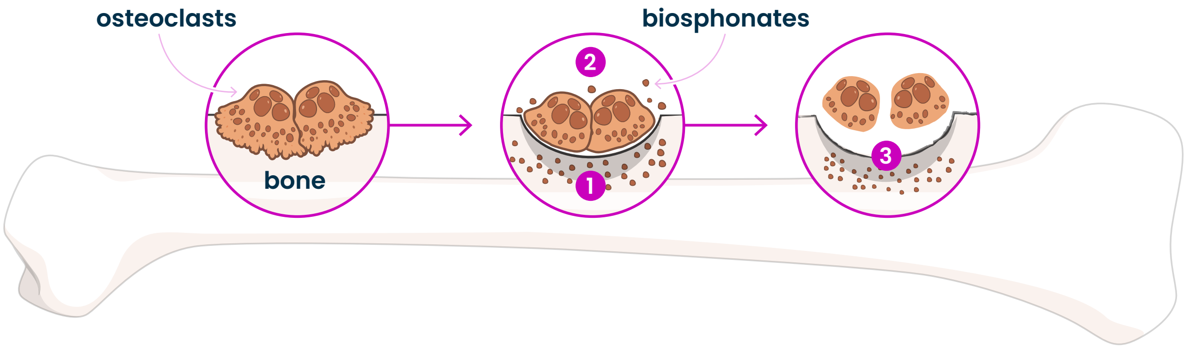
Bisphosphonates

A group of medicines called bisphosphonates is used to treat hypercalcaemia and/or bone disease in myeloma. Bisphosphonates are small molecules that attach to calcium and are taken up into your bones where they interrupt the bone breakdown caused by myeloma cells.

Bisphosphonates have many benefits, including:

- preventing or slowing further bone breakdown and damage
- reducing bone pain and the need for pain relief medicine
- reducing the chance of pathological fractures due to myeloma bone disease
- correcting and preventing hypercalcaemia (higher than normal levels of calcium in your blood caused by bone breakdown)
- improving the chance of bone healing and recovery of bone strength
- improving your quality of life by reducing pain and making mobility easier
- possibly having an anti-myeloma effect that can help with overall myeloma control.

How bisphosphonates work



1. Bisphosphonates build up in newly formed bone and in cells that break down bone (osteoclasts)
2. When bone is broken down, bisphosphonates are released and slow down the activity of osteoclasts
3. This leads to less bone being broken down

Who can benefit from bisphosphonates?

Bisphosphonates are generally recommended for anyone having treatment for myeloma. In some situations, there may be a medical reason not to have bisphosphonate treatment — these include having advanced kidney disease, low blood calcium levels, or active dental disease that requires having tooth extraction/s.

Bisphosphonates are not currently recommended for people with asymptomatic (smouldering) myeloma, or who have a single plasmacytoma (tumour of plasma cells).

What are the different types of bisphosphonates?

In Australia, there are two different types of bisphosphonates available to treat myeloma bone disease.

Medicine name	Brand names	How it is given
Zoledronic acid	Zometa®	Intravenous (IV) infusion over at least 15 minutes
Pamidronate disodium	Aredia®	IV infusion over 90–120 minutes

Your treating team will talk with you about the bisphosphonate they recommend for you and how often it should be given.

After some time, you may need your treatment schedule adjusted or to stop bisphosphonates altogether. This will depend on your risk of myeloma bone disease, overall health, and any side effects you experience.

> ***I felt reassured knowing that my treating team was keeping an eye on my bones with the scans I was having.***
>
> Shirley, Queensland

What are the possible side effects of bisphosphonates?

Bisphosphonates are generally well-tolerated. Always let your treating team know of any side effects so they can suggest alternatives or more ideas to help.

Side effects are usually mild and may include:

- **Fever and flu-like symptoms**, which can occur shortly after intravenous infusions. These symptoms are usually mild and last only a few hours. Paracetamol helps to prevent and manage these, if approved by your treating team.
- **Bone aches and pains** are usually linked to fever and flu-like symptoms. These can last for a day or two after each infusion and can be managed with paracetamol, if approved by your treating team.
- **Vein irritation or swelling** where you had the infusion. This is usually mild and lasts for only one to two days.
- **Eye problems**, such as redness, itching, soreness, sensitivity to light, swollen eyes, or blurred vision. Let your treating team know straight away if you develop any of these.
- **Mild nausea** is quite common and usually doesn't last for long. If nausea becomes a problem, ask your treating team for anti-nausea medicine.

More serious side effects with bisphosphonates are not as common and include:

- Lowered levels of electrolytes in your blood. Your treating team will check your electrolytes regularly and may prescribe supplements if your levels are very low.
- Osteonecrosis of the jaw (see box on following page).
- Kidney damage is the most significant possible side effect of bisphosphonates, especially from the ones given through a vein. Kidney damage is more likely if your kidneys are already affected by the myeloma or other conditions.

Your treating team will check your kidney function with a simple blood test before each infusion and will adjust the dose if needed.

To help protect your kidneys, it's important to drink at least 2 litres of water a day. You will also need to avoid any medicines that can affect the kidneys, such as nonsteroidal anti-inflammatory drugs like ibuprofen, aspirin, Celebrex® (celecoxib), Mobic® (meloxicam) and Voltaren® (diclofenac). Please ask your treating team if you are not sure which medicines are safe to take.

> *Each month, I go to the clinic to have my bisphosphonates. I am able to have them on the same day as my myeloma treatment, which saves on trips to the hospital.*
>
> Hanh, Northern Territory

> *I saw the dentist at the hospital prior to starting bisphosphonates, and have kept up with regular dental check-ups with my local dentist.*
>
> Val, New South Wales

What is osteonecrosis of the jaw (ONJ) and how can I avoid it?

ONJ is an uncommon but serious side effect of treatment with bisphosphonates and denosumab.

In ONJ, bones in the jaw become damaged and don't heal for a long time. Symptoms include pain, swelling and exposed bone around the tooth sockets and jaws.

The risk of ONJ is higher if you are having intravenous bisphosphonates, after long-term treatment, and after having invasive dental work such as tooth extractions, implants or oral surgery.

You can help to reduce the risk of ONJ by:

- having a full dental check-up and having any invasive dental work done ***before*** starting bisphosphonates
- keeping up a good oral care routine with regular brushing and flossing
- seeing your dentist every 6–12 months for check-ups
- avoiding any invasive dental work while on bisphosphonates. If you can't avoid invasive dental work, then you will need to stop treatment for a period and then restart bisphosphonates when your mouth has fully healed. Any dental work should be done by an oral surgeon experienced with ONJ and you should let your haematologist know about the plan for this as soon as possible.

> ***Even though I had no dental issues, I did end up with ONJ and needed to have teeth and pieces of dead bone removed. So even though ONJ is rare, it's really important to be aware of the risk and pay attention to any symptoms you may develop.***
>
> **Helen, Victoria**

Other ways to manage myeloma bone disease

Radiotherapy

Radiotherapy is used in myeloma to treat some specific problems, such as lesions and plasmacytomas, and to relieve pain, including bone pain. Not everyone with myeloma will need radiotherapy.

Radiotherapy works by breaking the chain of myeloma cell replication. It damages the cell's DNA, causing the cell to die. If you need radiotherapy, a radiation oncologist will prescribe the type, dose and frequency of radiotherapy that is suitable for you.

Before treatment, you will have an initial planning appointment with the radiotherapy team, which usually takes around 2 hours. The team will then follow-up with you to make your treatment appointment times. Your actual radiotherapy treatments will each take only a couple of minutes.

Denosumab

Denosumab is a different type of medicine that may be used to manage myeloma bone disease. It belongs to a class of medicines called monoclonal antibodies.

Denosumab works by attaching to and turning off a protein on the surface of osteoclasts that is overactive in people with myeloma. This over-active protein causes bone to breakdown faster than it can be repaired, so by turning off this protein, a healthy balance of bone building can be restored. Denosumab may be less toxic to the kidneys than bisphosphonates and so can be used in people with kidney problems. It is given as an injection once a month.

This treatment is not reimbursed by the Pharmaceutical Benefit Scheme (PBS) for myeloma. Some people may be able to access denosumab under special circumstances. Please ask your treating team if denosumab may be an option for you.

> *I had no symptoms of myeloma at all until I injured my shoulder while playing basketball. Scans revealed a plasmacytoma, which had caused weakness in my bones.*
>
> **Geoff, Victoria**

What else can I do to help my bone health?

There are some simple steps you can take to maintain your bone health and reduce the risk of osteoporosis, which can worsen the effects of myeloma bone disease:

- **Staying active** helps to strengthen muscles and bones, and has many other benefits for your overall health, mental health, and sense of wellbeing.

  Walking, swimming and stationery cycling are ideal ways to stay active.

  Resistance training or muscle strengthening exercises use the resistance of your own body weight, a resistance band, or weights to increase your muscle and bone strength. These programs need to be designed and supervised by an accredited exercise physiologist (EP) or physiotherapist (physio) to ensure they are tailored to your needs and are safe for you. An EP or physio can also provide advice on mobility aids.

  Our *Exercise and myeloma* infosheet has many ideas to help you stay active.

> ***I am keeping active, but I have decided to scale back on some of the riskier activities that I enjoy, like snowboarding, just while things settle.***
>
> **Ahmed, Western Australia**

- **Avoid high-impact exercises and contact sports**, such football, rugby, netball and squash, and activities with a high risk of falls, such as ice skating, roller skating, or skiing.

  Take extra care when bushwalking or hiking, ensuring the terrain suits your ability.

  Ask your EP or physio for more detailed and specific advice about exercise or sports that might be risky for you, and ways to modify them to make them safer.

  Your EP or physio can also help you find ways to make many everyday activities safer and easier for you.

- **Eat a healthy, balanced diet** that includes three serves of calcium-rich foods, such as dairy products, canned sardines or salmon with edible bones, and green vegetables like bok choy, broccoli, cabbage, kale and rocket every day.

  It's best to limit green vegetables that are very high in oxalates, which make it difficult for your body to absorb calcium. High oxalate vegetables include spinach and silverbeet.

Ask your doctor about your calcium and vitamin D levels. If they are low, you may need to take supplements to help improve your bone health — but remember not to take any supplements without medical advice.

Hypercalcaemia: When you have too much calcium in your blood

If you've been told you have hypercalcaemia (too much calcium in your blood), it's important to know that you do **not** usually need to restrict your calcium or vitamin D intake.

You may read information from other sources about restricting calcium and vitamin D when you have hypercalcaemia, but this is directed towards people whose hypercalcaemia has a different cause.

Hypercalcaemia in myeloma is generally managed with bisphosphonates to reduce bone breakdown, and by drinking plenty of fluids to dilute the calcium in your blood. Please ask your treating team for more information.

Living well with bone pain

Bone pain is the most common symptom of myeloma bone disease. It's very important to manage this pain well so that it has the least possible impact on your mobility and quality of life. The first step is to talk with your treating team, describing your pain and explaining how it affects you. This will help your team to work with you and develop the best plan to manage your pain.

Often, your bone pain can be relieved by treating the myeloma itself.

Other options for pain relief include radiotherapy, pain relievers, surgery, and other techniques such as acupuncture, using a TENS machine, gentle massage, and relaxation or distraction therapy. You can read more about these in our *Managing myeloma pain* infosheet.

When I was diagnosed with myeloma, I experienced lots of bone pain in my lower back and ribs. This improved once I started on treatment and my myeloma levels started to drop.

Maddie, Queensland

Learn more

You'll find more information about living as well as possible with myeloma in these resources available from myeloma.org.au:

RESOURCE	NAME	LINK
INFOSHEETS	→ 'Managing myeloma pain living well infosheet' → 'Exercise and myeloma living well infosheet' → 'Nutrition and myeloma living well infosheet'	Go to: myeloma.org.au Search for the document using the name following the icons

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More information and support

- **Watch Myeloma UK's Digital Infoday Session (webinar) on** myeloma bone disease. It includes information about treatments, supportive mechanical care (such as bracing), and offers practical tips, including how to exercise safely.
  - Go to myeloma.org.uk and search for 'Digital Infoday myeloma bone disease'.
- **Download Myeloma UK's** Infoguide on myeloma bone disease to read more detailed information about myeloma bone disease, its treatment, and future directions for treatment.
  - Go to myeloma.org.uk and search for 'Myeloma bone disease infoguide'.

Please note that not all information about tests and treatments for myeloma bone disease in the UK will be relevant for people in Australia. Medical and other benefits available for patients in the UK do not apply to patients in Australia (although there may be similar Australian benefits available).

- **Our Specialist Myeloma Nurses** are available on our Telephone Support Line to talk with you about any aspect of myeloma, its treatment and management.

  To book a 30- or 60-minute call with a Specialist Myeloma Nurse:

  call **1800 MYELOMA** (1800 693 566)
  Monday–Friday, 9am–5pm AEST/AEDT, or

  go to **myeloma.org.au** and click on the
  'Book a call with a Specialist Myeloma Nurse' button.

  email nurses@myeloma.org.au to contact a Specialist Myeloma Nurse at any time.

We hope you've learnt more about the way myeloma affects your bones, why it's important to treat myeloma bone disease, and you've found some new tips to manage your bone health.

The information in this sheet is not intended to replace medical care or the advice of your treating team. Please talk to your doctor and exercise physiologist or physiotherapist about their recommendations for treating and managing your myeloma bone disease.

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