Myeloma Australia

LIVING WELL INFOSHEET

Managing myeloma pain

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Things to remember

- At some stage, pain will affect most people living with myeloma.
- Each person's experience of pain is personal and complex, with physical and psychological parts to it. That's why managing pain often involves several different health professionals, medicines, treatments and tools.
- Common sources of myeloma pain include bone disease, peripheral neuropathy, infections, treatment side effects, and medical procedures.
- In myeloma, fatigue and pain are often linked together in a vicious cycle. Managing your fatigue can help manage your pain, so you can feel as well as possible.
- Communicating with your treating team about your pain and how it is affecting your life is the first step in managing your pain.
- There are many options for treating pain, including different types of medicines, other medical treatments, as well as physical, psychological and complementary therapies.
- It's important not to suffer in silence. Your treating team has many tools to help and will work with you to tailor a personal 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.

Understanding pain

Pain is a very common symptom of myeloma, affecting 80% of people living with myeloma at some point.

We experience pain when pain receptors in our nerve endings send a signal to the brain that there has been some damage. The brain responds by telling the body to protect itself, minimising potential harm to the body. Most pain is resolved once the cause of the pain is removed — this is called acute pain. Sometimes, pain continues even after the body has healed — this is called chronic or ongoing pain.

Our experience of pain is complex and has both physical and psychological parts to it. We usually think of pain as being linked to physical factors such as illness, inflammation, surgery or injury, but it is also linked to our experiences, memories and emotions. When you live with pain, especially ongoing pain, it can have a significant psychological impact, causing frustration, anxiety, a low mood, sleep problems and fatigue. In turn, these can affect the level of pain you feel and can spill-over into how you manage many other areas of your life.

Pain is also very individual. Two people can have very similar causes of pain, and yet feel very different sensations and levels of pain.

When you have myeloma, pain can have a big impact on your quality of life, making it difficult to get on with daily activities, maintain relationships, and cope with other symptoms. Your pain can also affect the people who are closest to you.

That's why having an individual pain management plan is such an important part of your myeloma treatment. This begins with communicating openly with your treating team and then working with them to find the right combination of medicines, treatments, tools and lifestyle adjustments to help manage your pain so you can experience an improved quality of life.

What causes pain in myeloma?

There are many potential causes of pain in myeloma: some pain is caused by the disease itself, and some pain can be a side effect of treatment.

Bone disease

Bone disease is the most common, and often the most challenging, feature of myeloma.

Bone disease happens because myeloma cells produce a protein that causes your bone to be broken down faster than it can be repaired, which can result in different complications and types of pain:

- **Bone thinning and damage and lytic lesions (holes in your bones)** caused by myeloma can result in dull, ongoing bone pain that may be localised or widespread, and the pain may be made worse with movement.
- **Plasmacytoma** is where myeloma cells collect on a bone or tissue and form a tumour that may cause pain.
- **Pathological fractures** can happen when your bones weaken and break from just a small amount of pressure, while compression fractures can result from thinning of bones in your spine (the vertebrae). Sudden or severe pain may be a sign of fracture.
- **Spinal cord compression** can be caused by a fracture or myeloma tumour, and can result in pain, weakness, tingling, loss of sensation, or problems passing urine or using your bowels. The pain often comes on as unexplained back pain that feels like a tight band and gradually becomes worse, and may radiate down to your bottom and legs. Or, the first signs of spinal cord compression may be problems controlling your bladder or bowels. Spinal cord compression is a medical emergency and you should always get immediate medical attention if you have any symptoms.

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.

"The bone pain I experienced in my back at diagnosis was intense! I thought it would never go away, but once I had radiotherapy and started treatment, I was pain-free after a couple of months."

Lucy, Queensland

Learn more

Managing myeloma bone disease is an essential part of living as well as possible with myeloma and reducing your pain. Read more in our information sheet, *Managing myeloma bone disease*.

Peripheral neuropathy

Peripheral neuropathy is a term used to describe damage to the nerves that make up the peripheral nervous system, which includes the nerves in your hands, feet, arms and legs. Although the pain caused by peripheral neuropathy can be quite different for each person, it is often described as causing sharp, burning or jabbing pain, increased sensitivity to touch, tingling, numbness, pins and needles, and altered sensations — such as feeling pain or heat when you touch something cold.

Peripheral neuropathy can be caused by the myeloma itself or by some of its treatments:

- paraprotein from myeloma cells can be deposited on nerves, causing damage to them
- the myeloma treatments, bortezomib (Velcade®) and thalidomide (Thalomid®) can be toxic to nerve cells, especially when used in high doses and for a long time.

Having diabetes, certain vitamin deficiencies, or drinking a lot of alcohol can also contribute to peripheral neuropathy and make it more difficult to treat.

Peripheral neuropathy may be mild at first and worsen over time, and can be easier to treat if it is picked up early. That's why it's important to let your treating team know as soon as possible if you develop any symptoms.

> ***"I would lie in bed at night and the bed sheets felt like razors against my toes and feet. I informed my treating team and the medicines they prescribed really helped me."***
>
> **Muzzafer, Victoria.**

Learn more

Our booklet, *Managing Peripheral Neuropathy — A guide for people with myeloma*, includes detailed information about peripheral neuropathy and how to manage it.

Cramps

Cramps are painful tightenings in the muscles of your calves, ankle or foot, and they often happen at night.

Cramps can be caused by myeloma itself and can also be a side effect of some myeloma treatments — such as thalidomide (Thalomid®), lenalidomide (Revlimid®) or pomalidomide (Pomalyst®).

Our Myeloma Support Nurses often suggest staying well hydrated, eating bananas and drinking tonic water or an electrolyte replacing drink (like Powerade®) to help prevent cramps. You may also find it helpful to stretch out your muscles before going to bed.

If cramps are an ongoing problem for you, talk to your treating team, who may recommend having your electrolyte levels checked and may prescribe magnesium to help.

Infections

Both myeloma and its treatments increase the chances of developing an infection, and some of these can cause pain as well:

- **Lung infections** such as pneumonia can cause chest pain, usually on one side of your chest. The pain is sharp and feels worse when you breathe and cough.
- **Urinary tract infections** can cause burning or stinging pain when you pass urine, and can sometimes cause lower back pain.
- **Shingles** is a viral infection in the nerve roots, caused by the chicken pox virus. The infection causes sharp, stabbing pain, burning, numbness, tingling and sensitivity to touch on the skin above the nerves affected. A red rash usually begins a few days after the pain starts. Some people experience ongoing pain for some time after their rash has gone. Early detection and treatment can help to reduce the pain of shingles and the chance of experiencing ongoing pain. The shingles vaccine is reimbursed for some people. Ask your doctor if this might be beneficial for you.
- **Mouth infections** such as oral thrush may cause mouth and throat pain and make it difficult to eat and swallow.

Your doctor will talk with you about your risk of infections. In some cases, they may recommend taking medicine to prevent infections, and will recommend vaccinations that are important for you.

Having a temperature of 38°C or higher is a common sign of infection. It's important to have a thermometer at home so you can check your temperature if you feel overly hot or shivery. Always get urgent medical attention for a temperature of 38°C or more.

Treatment side effects

Treatments that destroy myeloma cells can also damage healthy cells in your body, and this can cause unpleasant side effects which can be painful:

- **Diarrhoea and constipation** caused by some treatments can result in bloating, discomfort and stomach cramps.
- **Mucositis**, inflammation of the mucous membrane in your mouth and throat, can be a side effect of chemotherapy, especially from the high-dose melphalan given as part of an autologous stem cell transplant. Mucositis can cause painful inflammation and blisters that make it difficult to eat and drink.
- **Peripheral neuropathy**, which we have covered on page 4 of this infosheet, can also be a side effect of myeloma treatments.
- **Flu-like symptoms**, including fever, aches, and bone and joint pain, are common side effects of high-dose granulocyte-colony stimulating factor (G-CSF) injections, which are used to stimulate your body's production of stem cells before having an autologous stem cell transplant. These symptoms are usually a temporary and positive sign, meaning that your stem cell activity is increasing. The pain can usually be managed with paracetamol provided by your treating team. Some people may need strong pain relievers while having G-CSF injections. Contact your treating team if you are experiencing breakthrough pain — a flareup of your pain that happens even when you are taking regular pain relief.

Most of the pain associated with treatment side effects is short-term and can be either prevented or well-managed, and will usually improve or go away once you have completed treatment. Remember to talk with your team about the best way to prevent and manage treatment side effects.

Tests and medical procedures

There are many different tests, investigations and procedures that you'll need before, during and after treatment for myeloma. These include blood tests, and bone marrow aspirates and biopsies.

You may have a central line, also called a central venous access device (CVAD) or central venous catheter (CVC) inserted. This involves having a small, soft tube called a catheter put in a vein that leads to your heart. A central line is used for stem cell collection and transplantation, and may be used for other treatments that are given by infusion, and for taking blood samples. Once a central line is in place, it means you don't need to have a canula put into your vein each time you need an infusion or blood taken.

These procedures may cause some short-term discomfort and pain, which you can usually manage well with relaxation and distraction techniques, and paracetamol provided by your treating team.

If your pain does not improve with paracetamol, let your treating team know so they can check for any complications that might be causing your pain.

Fatigue and pain

Fatigue, which is also called cancer-related fatigue or CRF, is one of the most common symptoms of myeloma, and one of the most difficult to live with. This type of fatigue is a feeling of extreme tiredness or exhaustion that is very different from everyday fatigue, and is not easily relieved by sleep or rest. Cancer-related fatigue can affect you physically, mentally and emotionally.

Fatigue and pain are often linked together in a vicious cycle, which is why it's so important to get on top of both as best you can.

For example, pain associated with myeloma can make it difficult to sleep well. Not getting enough good-quality sleep can add to fatigue, lower your pain threshold, and mean you're less likely to be active and do things you usually enjoy. This can make your pain feel worse, and lead to a low mood or leave you feeling stressed, anxious, and irritable. These feelings can feed into the cycle, impacting your quality of sleep and experience of pain and fatigue even further.

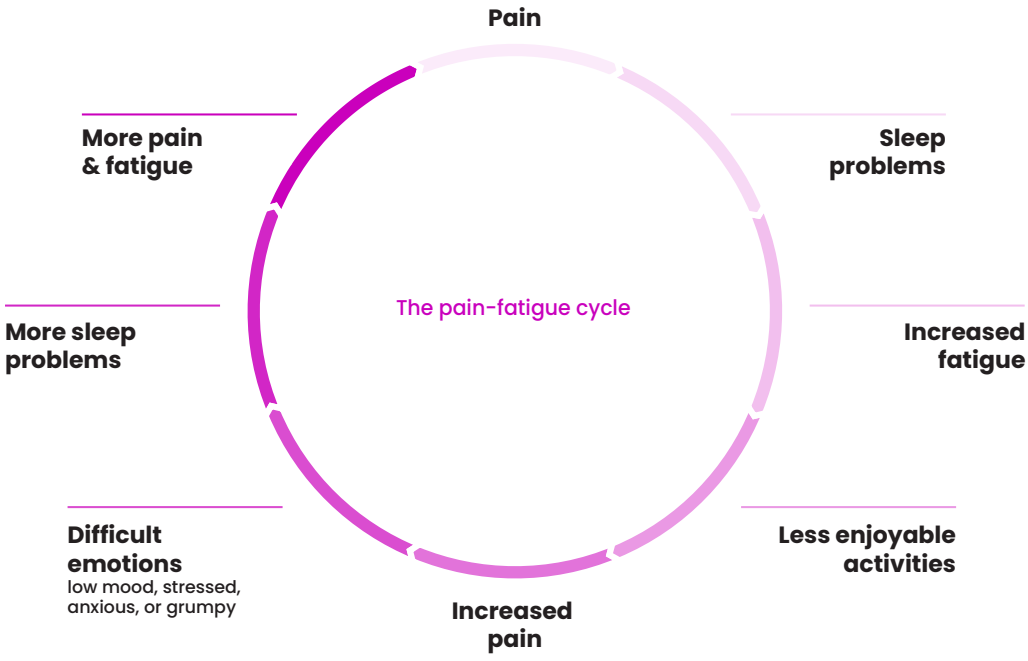
While all this sounds very gloomy, the good news is that there are many positive steps that you and your treating team can take to help better manage both your fatigue and pain, and help you feel as well as possible.

> ***"I was fatigued because the pain was really bad at night. With my doctor's approval, I tried a sedative and my sleep quality improved – I then felt more able to cope with and deal with my pain."***
>
> **Arthur, Tasmania.**

Learn more

Our infosheet, *Managing fatigue*, explains more about the different types and causes of fatigue in myeloma and the different strategies and tools that can help.

The image (on the right) shows the relationship between pain and fatigue, and how each can make the other worse



Talking about pain with your treating team

Clearly describing your pain and how it affects your daily life will help you and your treating team to work out the best pain management plan. It will also help to give both of you a baseline so you can measure how well your pain management plan is working.

Your team may ask you:

- Where is the pain?
- When did it begin?
- Does it move anywhere else?
- What does it feel like? Is it sharp, dull, throbbing, burning, or some other sensation?
- Does pain prevent you from doing daily activities such as showering, dressing, working, gardening or walking?
- Does anything make your pain feel worse or better?
- What pain relief have you tried? How much has it helped?
- Is the pain constant? If not, when does it occur? Are there different days or times that it is worse?
- Has your pain recently become worse?
- Do you have any other symptoms that occur with your pain?

Do your best to answer these questions and explain your pain honestly. It can be difficult to talk about pain and to admit how much it affects you, especially if you are used to 'being strong and carrying on'. But the more honest you can be, the more your treating team can help.

Treating pain

The aim of treating pain is to provide you with adequate, constant relief, with as few side effects as possible. Often, myeloma pain can be relieved by treating the disease itself, and so your response to treatment can play a big role in reducing your pain and improving your quality of life.

Every person's experience of pain is different, and this means that pain management needs an individual approach so that the best treatments can be used to achieve the most relief. It often takes a process of trial and error to find the best plan to help control your pain.

Fortunately, there are many different pain relief options available for myeloma-related pain. With the right plan, most people can have more control over their pain, which can make life easier to manage. We have covered some of the most commonly used tools for managing pain in the next few pages.

Medical pain management options

Anti-myeloma treatments

If your pain is caused by the effects of myeloma itself, then starting treatment and reducing the amount of the disease in your body can provide effective pain relief. If your myeloma responds to treatment, you may be able to reduce or stop taking pain relief medicine.

Pain relief medicine (analgesia)

There are many types of pain relief medicines (also called analgesia) available. Each has different actions and side effects and suit different people at different times. Often, your treating team will prescribe more than one type of pain reliever at the same time to provide you with the best relief.

Pain relief medicines come in many different forms, including tablets, liquids, medicinal lollipops, nasal sprays, skin patches, and injections.

Some of the more commonly used pain relievers include paracetamol for mild-moderate pain, different types of opioids for moderate-severe pain, as well as medicines for nerve-related pain and medicinal cannabis (also called medicinal marijuana).

Your treating team will talk with you about the benefits and risks of each type of medicine and will explain why they have recommended specific pain relievers for you.

Your doctor will usually start you on a low dose of a pain reliever and then increase your dose until your pain is well controlled, as long as you are managing with side effects.

Like all medicines, pain relievers can cause side effects. Common side effects include constipation, drowsiness and nausea. These can usually be prevented or well-managed. Always let your treating team know about any side effects you experience so they can adjust your plan to keep controlling your pain while reducing side effects.

It's important to know that nonsteroidal anti-inflammatory drugs (NSAIDs) are not recommended for people with myeloma, as they can cause kidney damage. These medicines include 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.

Slow-release pain relievers for chronic pain

If you have chronic (ongoing) pain, your doctor may prescribe a slow-release pain reliever. These medicines are usually taken twice a day and are designed to provide low levels of background pain relief.

It's important to take these medicines as prescribed to decrease the chance of breakthrough pain. If you do experience breakthrough pain, you can take additional prescribed pain medicine.

Make sure you let your treating team know how much pain medicine you are needing in addition to the slow-release medicine, as it may mean your doctor needs to increase the dose of the slow-release medicine to provide more stable pain control.

> ***"I made some temporary lifestyle adjustments to the activities that I usually enjoy while my treating team and I were increasing the dose of my pain relievers. Once this was done, I was able to reintroduce my favourite activities."***
>
> **Xia, Western Australia**

Remember that everyone is different and it may take a few attempts to settle into a good pain-relieving plan. Keep talking with your treating team or palliative care team so you can work out the best plan together.

Where the palliative care team fits in

Complex pain is often managed by a palliative care team, which can be made up of doctors, specialist nurses, psychologists, physiotherapists and occupational therapists who have expertise in cancer care and pain management.

There is a lot of misunderstanding about palliative care, with many people thinking it is only about providing end of life care. But palliative care is actually all about providing specialist care in pain management and symptom control at all stages of an illness. You can be referred to a palliative care team at any time in your treatment pathway with myeloma, so it's helpful to be open to how this team can help you.

The palliative care team has many available pain management tools and can provide guidance on which treatments might be the most helpful, and can also provide holistic support for you, your family and carers.

Learn more

Read more about bone disease and bisphosphonates in our *Managing myeloma bone disease* infosheet.

Bisphosphonates

Bisphosphonates are a group of medicines used to help treat and prevent myeloma bone disease. They are effective in reducing the chance of fractures, and are also very effective in relieving bone pain and the need for other pain relief medicine.

Radiation therapy

Radiation therapy (which is also called radiotherapy), can be effective in reducing myeloma cells in bones and soft tissue, and therefore help to treat localised bone pain.

Radiation therapy is also effective in treating spinal cord compression, where treatment should be started as soon as possible to prevent permanent damage.

Surgical procedures

There are two surgical procedures, percutaneous vertebroplasty and balloon kyphoplasty, that are sometimes used to treat vertebral fractures. These procedures involve injecting surgical cement into the spine to relieve pain and strengthen the vertebrae. Your doctor will very carefully consider whether the benefits of one of these procedures outweigh the risks and will discuss this with you.

Physical, psychological and complementary therapies

As well as medical treatments for pain, there are many physical, psychological and complementary therapies that can be used together with *medical treatments to help manage your pain.*

It's often helpful to have the expert guidance of allied healthcare professionals such as a physiotherapist (physio), exercise physiologist or occupational therapist, and a psychologist to help you find the best range of tools that work for you.

We've included information about some of the pain management tools that have been helpful for other people with myeloma below. Please remember that not all therapies are suitable for all people, so always ask your treating team about any new therapies you are planning to try.

"I worked with my treating team and pharmacist to look at complementary therapies that could help alleviate my pain whilst not interfering with my treatment medicines."

Elena, New South Wales

Transcutaneous electrical nerve stimulation (TENS)

A TENS machine is a small, battery-powered device with leads that connect to sticky pads that you place on your body near painful areas. The machine delivers very small electrical currents to the skin that are thought to affect the way that pain signals are sent to the brain, encouraging the brain to release endorphins, and acting as a natural pain reliever in your body. TENS machines are inexpensive and can be bought or hired from most physios or pharmacies.

Acupuncture

Acupuncture is a type of traditional Chinese medicine where a trained professional inserts very thin needles into specific points in your body that relate to the types of symptoms you are experiencing.

Several research studies in people with myeloma have shown that acupuncture can help reduce peripheral neuropathy, pain and the need for pain relief, while increasing overall wellbeing.

Always talk to your treating team before trying acupuncture, and take extreme care if you have an active infection. Acupuncture appears to be safe for people with thrombocytopenia (low platelet counts).

Massage therapy

Gentle massage can be useful in relieving muscle pain, tension and cramps.

If your platelet count is low, check with your treating team first if it's okay to have a massage.

Tell your massage therapist that you have myeloma and that forceful massage can cause bone damage and bruising. It's ideal to find an accredited oncology massage therapist who will know how to tailor massages to your needs.

Visit the Australian Massage Directory and choose 'Oncology Massage' from the 'Type of Treatment' dropdown list. Enter your suburb or postcode to search for an accredited oncology massage therapist in your area.

Hot and cold packs

Using hot and cold packs can be effective in providing short-term pain relief and can be helpful for cramps. Often, alternating between hot and cold works best. It's important to wrap hot and cold packs in a protective layer, like a hand towel, so that you're not applying heat or cold directly to your skin. This is especially important if you have peripheral neuropathy that's caused numbness or altered sensation to an area.

Relaxation, meditation and distraction

Relaxation techniques can help to ease muscle tension, improve sleep, and increase your overall feelings of wellbeing, helping you to cope better with pain and the ongoing challenges of living with myeloma. Relaxation practices often focus on deliberately relaxing each of the major muscle groups in your body and using deep, conscious breathing.

Meditation is the practice of slowing down and observing your mind, and is another way of encouraging feelings of wellbeing and managing pain. It can be as simple as sitting in a quiet place and focusing on your breathing for a few minutes. Some meditation and relaxation practices include visualization exercises, which can also be helpful.

You can download free guided relaxation and meditation exercises on your smartphone, and you can also find these on music streaming services. Some people prefer to join a class to learn these techniques. There may be classes available at your cancer treatment centre or at a local community centre.

Distraction therapy is simply a way of taking your mind off pain for a short period. You might like to try watching TV, reading, listening to podcasts or music to see what works best for you.

- Some hospitals and cancer support groups offer meditation classes. You'll also find classes in the community, online and on smartphone apps.
- *Finding calm during cancer* is a Cancer Council podcast that includes guided meditation and relaxation exercises.

> ***"Exercising, mediation and spending time doing what I love were a good distraction to the pain I was experiencing."***
>
> **Jeff, Victoria**

Correct positioning

Your body positioning, including the way you sit or lie down can help to relieve pain. Try moving into different positions to get comfortable, using supportive pillows or cushions to help, or asking your physio or occupational therapists for more positions to try.

Exercise

Moderate gentle exercise such as walking can strengthen your muscles to support painful areas, and also helps to improve your overall health and wellbeing, lifting your mood, improving sleep and distracting from pain. It's important to find a balance between regular activity and rest, allowing your body time to recover.

Learn more

Learn more about the many benefits of staying active and how to do this safely in in our *Exercise and myeloma* infosheet.

> ***"Don't sit at home in pain. Tell your doctor or nurse. They can help!"***
>
> **Rishi, South Australia**

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 bone disease living well infosheet' → 'Fatigue and myeloma living well infosheet' → 'Exercise and myeloma living well infosheet' → Managing Peripheral Neuropathy – A guide for people with myeloma	Go to: myeloma.org.au Search for the document using the name following the icons

More information and support

- **Download Cancer Council Australia's booklet**, *Understanding Cancer Pain*, which includes more detailed information about understanding and managing pain, and different pain medicines.
  - Go to cancervic.org.au and search for 'understanding cancer pain'.
- **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 found some helpful ideas to help you manage pain so you can experience a greater sense of wellbeing while living with myeloma.

The information in this sheet is not intended to replace medical care or the advice of your treating team. Please talk to your team about any pain you are experiencing. They have many tools to help and will work with you to tailor a personal pain management plan so you can enjoy the best possible quality of life.