



### About us

The Leukaemia Foundation is Australia's peak body for blood cancer, funding research and providing free services to support people with leukaemia, lymphoma, myeloma and related blood disorders.

We invest millions of dollars in the work of Australia's leading researchers to develop better treatments and cures and provide free services to support patients and their families.

We receive no ongoing government funding and rely on the generosity of the community and corporate sector to further our Vision to Cure and Mission to Care.

### We can help you

Our range of free services supports thousands of Australians, from diagnosis, through treatment and beyond. To learn more, please call 1800 620 420 to speak with one of our Support Services team.

### You can help us

There are many ways that you can help us to improve the quality of life for people with blood cancer. From making a donation, to signing up for an event; from volunteering, or joining us as a corporate sponsor - please call 1800 500 088 or go to [www.leukaemia.org.au](http://www.leukaemia.org.au) to learn more.

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**Pain is 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.'**  
**([www.iasp-pain.org](http://www.iasp-pain.org))**

Two important points to note from this definition are:

- pain is both a physical *and* an emotional experience; and
- pain may be the result of potential tissue damage, as in the case of inflammatory conditions which, when healed, improves.

#### **What happens if pain is not treated?**

Everyone has experienced pain in some form or another. It serves an essential protective function as we move about in a potentially hazardous world. When pain occurs in myeloma, it serves to warn people of problems such as the presence of disease in the bones. However, in most people with myeloma, pain can continue for many weeks or months (known as *chronic pain*) and serves no protective function.

Chronic pain takes its toll on people with myeloma. It leads to tiredness, poor sleep, low mood, and interferes with movement or activities. Research tells us that untreated or inadequately treated pain will lead to more severe and stubborn pain as the body *turns up the pain volume* until you do something about it. For example, recall the last headache you had and did not treat until it was really, really bad. By this stage, paracetamol sometimes does not work.

#### **Why do people with myeloma have pain?**

About 58% of people with myeloma have pain when they are diagnosed. This is common because myeloma cells invade the bones, causing them to inflame. This inflammation triggers pain receptors in the bone. In more severe cases, myeloma in a bone causes weakening and fractures (breaks) and sudden, severe pain.

Myeloma can develop in the bones of the spine. Sometimes, the bone may become weakened and put pressure on the spinal cord. This is called *spinal cord compression* and may cause symptoms such as pain, muscle weakness and sometimes tingling and numbness of the limbs. If the lower spine is affected, it also may affect how the bowel and bladder work.

If you have weakness, pain, tingling or numbness in your legs, it is very important to tell your doctor or specialist nurse immediately, so treatment can be given as soon as possible, to prevent permanent damage.

Spinal cord compression is usually treated with radiotherapy. Steroids also are given to help reduce pressure on the spinal cord and sometimes surgery is needed to repair or remove the affected bone.

It is important to be able to assess or rate your pain as this can give your treating team an idea on how to approach treating your pain. Here are some questions your treating team may ask in managing your pain.

- How does your pain rate on a scale of 0 (no pain) to 10 (worst pain)?
- What words best describe your pain (e.g., dull, sharp, shooting or aching)?
- Does anything make the pain better or worse?
- How does your pain affect your everyday activities?
- How does the pain affect your sleep?

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### How can pain be managed?

The most important treatment for myeloma pain is treatment of the myeloma itself. As you would expect, removing the cause of the pain will improve (lessen) the pain. Myeloma treatment may include chemotherapy, new agents or radiotherapy. Fractures that result from weakened bones are usually treated surgically. Surgeons can insert plates and rods to support fragile bones. Bone-strengthening medications, like Zometa®, can help improve pain over a period of several weeks. Unfortunately, treatment of the myeloma may take some time.

While waiting for your bones to heal, it is important to use pain medications to avoid the harmful effects of pain, as described above. Simple pain medications like paracetamol and anti-inflammatories can be useful for milder pain. Be careful of stomach irritation with anti-inflammatories and always talk to your doctor before using these drugs.

When strong pain becomes a problem, it is usually not sufficient to rely on paracetamol and anti-inflammatories. You may be prescribed paracetamol with codeine (e.g., Panadeine, Panadeine Forte, Codalgin), morphine (e.g., MS Contin), oxycodone (e.g., Endone, OxyNorm, OxyContin) tablets/capsules, or even fentanyl patches (e.g., Durogesic). Use these medications only as directed by your doctor.

Common side-effects of these drugs can include:

- nausea;
- loss of appetite;
- constipation;
- drowsiness;
- dizziness;
- blurred vision; or
- difficulty passing urine.

Most of these side-effects can be prevented and/or managed effectively so it is important to let your doctor/nurse know if you experience any side-effects. You must not drive a motor vehicle or operate heavy machinery until approved by your doctor. Although many people believe these medications can cause addiction or tolerance (becoming immune to the pain-relieving benefits), this does not occur when used for cancer-related pain. When the myeloma is treated, pain medications can be reduced in some instances.

Additional drugs that are not normally used as painkillers also be helpful in certain circumstances. For example, anticonvulsant (anti-seizure) medications like carbamazepine and gabapentin, and antidepressant drugs like amitriptyline may help relieve neuropathic pain that arises mainly from nerve damage. Some of these medications can slow or stop pain signals sent by nerve cells to the brain. Steroids, particularly dexamethasone, sometimes may be used to relieve bone pain.

The following procedures can help with the pain.

**Percutaneous vertebroplasty** repairs a compression fracture by injecting a special cement into the vertebrae. This procedure, carried out only in specialist centres, can help stabilise the bone and relieve pain. Side-effects are uncommon but can include infection or damage to the nerves in the spine.

**Balloon kyphoplasty** may be used to improve the strength of the spinal bones, which can relieve pain and help people move around more easily. It involves inserting a balloon-like device, called an inflatable bone tamp, into the vertebrae and then slowly inflating it. Once the bone returns to its normal height, it can be injected with bone cement. This is a newer technique, carried out only in specialist centres. Possible side-effects are similar to those of percutaneous vertebroplasty.

Your doctor or specialist nurse will explain more about percutaneous vertebroplasty or balloon kyphoplasty if they feel either treatment is appropriate for you.

### How is pain medication taken?

There are varying ways to take analgesics, e.g., some patients can receive an opioid called fentanyl through a patch applied directly to the skin. This patch supplies a steady stream of medication and needs to be changed once every 2-3 days. Other opioids now come in a sustained-release form, so you don't need to take frequent doses of medication. Also, people with severe chronic pain can carry a small, portable pump that continuously dispenses pain medication intravenously.

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Fentanyl also is available in the form of a lozenge on a stick (like a lollipop) and as a tablet that dissolves in the mouth. As you suck on the lozenge, or as the tablet dissolves, the medication is absorbed through the mucosal membrane that lines your mouth, which can provide rapid pain relief. This form of medication is especially useful if you experience pain when moving or feel a sudden, temporary flare of pain.

Over-the-counter medications for managing pain, such as nonsteroidal anti-inflammatory drugs (NSAIDs, including aspirin and ibuprofen), should be avoided unless your doctor specifically says you can take them. These drugs can interfere with cancer treatments or interact with other medications in harmful ways. If you have any questions about the use of NSAIDs, ask your doctor.

### **Are there any other measures that can help the pain?**

Some patients find that complementary pain control techniques such as relaxation and visualisation can reduce the intensity of pain when used in combination with pain medication. Massage and acupuncture also can provide relief for some patients.

**The Leukaemia Foundation publishes the guides: 'Understanding Myeloma. A guide for patients and families'; 'Understanding Autologous Transplants'; and 'Understanding Allogeneic Transplants'.**

*It is not the intention of this fact sheet to recommend any particular form of treatment to you. You need to discuss your particular circumstances at all times with your treating doctor.*

For more information, freecall 1800 620 420  
email [info@leukaemia.org.au](mailto:info@leukaemia.org.au) or visit [www.leukaemia.org.au](http://www.leukaemia.org.au)