Myeloma Australia

information sheet

Pain and Myeloma

At some point pain affects up to 80% of people with myeloma. The type and intensity of pain varies considerably and affects each person differently. Pain can be localised to one area of the body or many different areas.

This information sheet explores the main types and causes of pain in myeloma, as well as different approaches used to effectively manage pain. It also emphasises the need for honest communication with the doctor about the impact that pain is having.

Causes of Pain in Myeloma

Myeloma bone disease

Bone disease is very common and often the most debilitating feature of myeloma. Any bone may be affected however, the areas usually involved include the middle or lower back, the hips, the rib cage and the long bones of the upper arms and legs.

Bone disease occurs as a result of myeloma cells producing a protein that causes the bone to be broken down faster than it can be repaired. Sometimes the bones can become so weak that they can break without undue force or injury – this is called a pathological fracture.

The thinning of the vertebrae (bones of the spine) can also result in fractures. They tend to collapse and become compressed. This is known as a vertebrae compression fracture and can be very painful.

Sometimes, a group of myeloma cells can collect on a bone or tissue forming a tumour called a plasmacytoma. If evident, pain may be experienced in this area.

Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves that make up the peripheral nervous system. In myeloma, the nerves that are most commonly affected are those of the hands, feet, arms and legs

There are several possible causes of peripheral neuropathy in myeloma including treatments, myeloma cell infiltration of nerve tissue and complications such as infection.

Common symptoms of peripheral neuropathy include pain, numbness or a ‘pins and needles’ sensation in the affected nerves.

For more information about peripheral neuropathy please see Myeloma Australia’s Managing Peripheral Neuropathy Book – A guide for people with myeloma on their website www.myeloma.org.au or by phoning head office for a copy 1800 693 566

Infection

Myeloma and/or the treatments increase the likelihood of an infection some of which can be accompanied by pain.

A fever, which is a temperature of 38°C or above, is a sign of infection. It is recommended that patients have a thermometer at home and check their temperature if they feel excessively warm or hot, or develop the shakes (rigors).

If a patient's temperature is 38°C or above medical attention must be sought immediately.

In some cases prophylactic antibacterial and antiviral medication may be prescribed to prevent infections. It may also be appropriate to have the flu vaccination. The doctor will advise if any of these measures are necessary.

Sore mouth

A sore mouth (or 'mucositis') is one of the side effects of chemotherapy, especially when it is given in high doses before a stem cell transplant. The lining of the mouth can become red and inflamed and can sometimes result in extreme pain and discomfort. Fortunately, this is normally a temporary side effect and the mouth should return to normal once recovered from treatment. Speak to the treating team for help in managing this symptom and the resulting pain.

Describing and assessing pain

In order for the doctor or nurse to treat pain effectively it is important that they have a detailed explanation of the pain. They will ask a range of questions to try to establish the exact nature of the pain – this helps to work out which treatment is most appropriate and also provides a baseline measure to see which pain interventions are working.

It may be helpful, therefore to consider asking these questions before speaking with the doctor or nurse:

- Where is the pain?
- Does it move anywhere else?
- When did it begin?
- What does it feel like? Sharp? Dull? Throbbing? Burning? Steady?
- Does it prevent daily activities from being carried out?
- What makes it worse?
- What makes it better?
- Which pain relief has already been tried?
- Is the pain constant? If not, how many times a day (or week) does it occur?

Some people find that keeping a diary of their pain, over a few days, helps them to describe it more accurately and detect any triggers, or periods of the day when it is worse.

When documenting pain it is useful to rate the pain using a scale of 0-10. 0 being no pain and 10 the worst pain imaginable. This helps the doctor or nurse to assess the pain at baseline and evaluate how effective pain relief measures have been.

It is also possible to experience other symptoms associated with pain. These can include nausea, headaches, dizziness, weakness, drowsiness, constipation and or diarrhoea.

Pain can also have a huge impact on many aspects of a person's well being including sleep and emotions. It is important to let the GP, specialist or nurse know if living with pain is affecting mood and sleep.

It is also important to note that increasingly severe back pain in the presence of changes to bladder and bowel control can be signs of a serious complication. If these symptoms arise, seek urgent medical attention.

Treatment for pain

There are many different treatment options available and most hospitals will have access to a specialised pain and symptom control team or palliative care team which consists of a range of professionals who are experts at assessing and relieving pain. The approach of managing of pain is more likely to involve many different approaches including medications, non drug therapies such as radiotherapy and non medical treatments.

The aim of any pain relieving treatment is to provide continuous pain relief, whenever possible, with a minimum of unwanted side-effects. Pain control must be tailored specifically to the individual and must be regularly reviewed.

Medical Treatments

Bisphosphonates

Bisphosphonates such as Zometa® (zoledronic acid), Aredia® (pamidronate) and Bonefos® (clodronic acid) are a specific group of drugs that inhibit bone destruction in myeloma. They have been shown to reduce bone pain and the need for strong pain killers as well as reducing the likelihood of pathological fractures.

Bisphosphonates treatment is recommended for all patients with myeloma requiring treatment whether or not bone lesions are evident.

Chemotherapy

Chemotherapy is a key component of pain management as it is aimed at treating the myeloma itself, which may be the underlying cause of pain. If the myeloma responds to chemotherapy treatment then it is possible that the pain will decrease and pain medication will be reduced or even ceased.

Any change in pain medication must be done in consultation with a doctor in a safe and gradual way to avoid complications.

Radiotherapy

Radiotherapy can be a very effective measure in relieving bone pain in localised areas throughout the body. It is also effective in relieving pressure on the nerves or spinal cord.

Surgical interventions

Vertebroplasty and balloon kyphoplasty are two minimally invasive surgical procedures used for stabilising or reversing vertebral compression fractures. These procedures may occasionally be used to offer considerable pain relief as well as strengthening the bones of the vertebrae.

Painkillers

Painkilling medications (also known as 'analgesia') are often prescribed to try to gain control of pain. An individual approach must be taken in order to achieve pain control for each person and it often comes down to trial and error as to what works best. A specialist pain team or palliative care team may be involved to help manage pain medications to make sure that there is good control and that the side effects are minimal or acceptable.

Many people are reluctant to take pain killers, however, it is important to note that, when morphine or any other strong painkiller is used to treat severe pain, they are not addictive. It is not a sign of weakness to admit to needing help with pain.

As with any medication, most painkillers have side-effects, most of which, if caught early, can be managed effectively. Therefore, it is extremely important that the treating team are aware of any side-effects experienced.

Some of the common side-effects are: constipation, nausea, loss of appetite and drowsiness. When prescribed analgesia the doctor or nurse will explain which side-effects are most likely to be experience.

The painkillers that are most commonly used in myeloma are listed in the table below. Additional drugs that are not normally used as painkillers may also be helpful in certain circumstances e.g. amitriptyline, gabapentin or pregabalin may help relieve neuropathic pain (caused by damage to, or pressure on nerves). Steroids, such as dexamethasone, may also be used to relieve bone pain.

The evidence for the use of medicinal marijuana is still emerging and availability varies around the country. Each case is individual. Consult the treatment team to discuss the best pain relief options available.

Over the counter non-steroidal anti-inflammatory painkillers (e.g. ibuprofen) are not generally recommended for use in myeloma as they can contribute to kidney damage and can increase the risk of bleeding.

Commonly used painkillers in myeloma

Class	Examples	Comments
Simple non-opioid analgesics	Paracetamol	Useful in mild to moderate pain.

Weak opioids	Provide effective pain relief for moderate pain, e.g. Panadeine Forte, tramadol.	Confusion and drowsiness may be experienced initially: can cause constipation: caution required in renal impairment.
Strong (natural) opioids	Provide effective pain relief for moderate to severe pain. Morphine – as liquid or tablets can be converted to slow release preparations when daily requirements are established e.g. MS Contin	As above
Synthetic Opioids	Provide effective pain relief for moderate to severe pain; some can be less toxic than natural opioids Include: -Oxycodone – may be given orally (immediate or slow release formulations) e.g. -Oxycontin, targin, endone, hydromorphone -Fentanyl or buprenorphine – given as slow release patches	As above
Others	Gabapentin and pregabalin, amitriptyline, carbamazepine (neuropathic pain).	
	Medicinal Marijuana.	

Non-Medical Treatments

There are a range of non-medical interventions that can be used to help relieve pain, some of which are listed below. It may also be useful to enlist the help of some allied health professionals such as an occupational therapist, physiotherapist and psychologist to help manage pain.

It is important that the treating team are aware of any non-medical interventions to ensure no inadvertent harm is caused.

TENS machine

TENS (Transcutaneous Electrical Nerve Stimulation) machines deliver small electrical pulses to the body via electrodes placed on the skin. TENS machines are thought to affect the way pain signals are sent to the brain. TENS machines can be bought or hired from physiotherapists or pharmacies.

Acupuncture

Acupuncture is part of traditional Chinese medicine and uses the balance of the body's own life force to restore wellbeing. Acupuncture can be used to alleviate pain and to relax muscles.

Gentle massage

Gentle massage can be used to relieve muscle pain and tension and can be both therapeutic and relaxing. The massage therapist needs to be aware of a diagnosis of myeloma, including the details of any bone complications that may be present.

Hot and cold packs

Hot water bottles and ice packs can be very effective in providing short term pain relief. It's best not to apply them directly onto the skin and often alternating between hot and cold works best.

Relaxation techniques

Tense muscles can contribute to pain. Learning relaxation techniques can not only ease pain but can help people cope with it better. This includes mindfulness meditation and visualisation exercises.

Correct positioning

Often the way we sit, or lie down can affect pain. Use supportive cushions or pillows and ask to be seen by a physiotherapist or occupational therapist for expert advice.

Self-Help Strategies

As well as the non medical treatments listed above, things that may control pain include:

Asking for help when needed

Family and friends are usually very willing to offer help but it can be hard to accept. Allow them to cook or help with shopping or gardening. It will make life easier and make them feel useful.

Taking painkillers regularly as prescribed

Don't wait until there is pain. It is much more difficult to gain control of pain when it has been left to escalate. Take the pain relieving medication as prescribed by the doctor. This will help them assess if the type and dose of medication is adequate.

Distraction therapy

Some people find that watching TV, reading, or listening to the radio can help by taking their mind off the pain for a short while.

Achieving a balance between regular rest and activity

Moderate gentle exercise (e.g. walking) will strengthen the muscles, elevate mood and help to distract from pain. It is also important to set aside time to rest each day to help the body recover.

Be honest with treating team

Let the treating team know about the level of pain being experienced, especially any new sites of pain or if it is increasing in intensity.

Talking about feelings

Anxiety and stress can aggravate pain therefore talking about worries and concerns is very important. Enlist the help of trained counsellor or psychologist through the GP or hospital.

CONCLUSION

Pain may affect the majority of patients with myeloma at some point: however open and honest communication with the treating team about pain, and using the correct pain management interventions, it can be controlled, allowing for an improved quality of life.

The information in this fact sheet is not intended to replace medical care or the advice of a physician.
A doctor should always be consulted regarding diagnosis and treatment.

For further information please contact one of our Myeloma Support Nurses on our Support Line:
1800 MYELOMA (1800 693 566)
or visit our website: **www.myeloma.org.au**

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