

## Pain

### Pain and myeloma

Pain is the most common symptom of myeloma and will be experienced by up to 80% of myeloma patients at some point. The type and intensity of pain will vary considerably and will affect each person differently.

Living with pain can have a huge impact on all areas of your life, especially if it is untreated or is poorly managed.

### What are the causes of pain in myeloma?

There are many potential causes of pain in myeloma including:

#### **Myeloma bone disease**

Bone disease is the most frequent and often the most debilitating feature of myeloma, therefore bone pain is a very common symptom. The areas usually affected include the middle or lower back, the hips and the rib cage. The long bones of the upper arms and legs can also be affected.

Bone disease occurs as a result of myeloma cells in the bone marrow affecting the surrounding bone, causing the bone to be broken down faster than it can be repaired. This results in gradual thinning and weakening of bones.

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. When vertebrae fracture they tend to become compressed and collapse. This is known as a compression fracture and can be very painful.

#### **Peripheral neuropathy**

Peripheral neuropathy is the term used to describe damage to the nerves that make up the peripheral nervous system.

The causes of peripheral neuropathy in myeloma are varied and can include common treatments (e.g. VELCADE®, thalidomide), presence of the paraprotein in the nerve cells and common infections (e.g. shingles).

In myeloma the nerves that are most commonly affected are those of the hands and feet.

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

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## **Infection**

Myeloma can weaken the immune system leaving you more susceptible to picking up recurring infections, some of which can be accompanied by pain. Common infections include chest infections, kidney infections and viral infection shingles.

## **Sore mouth**

A sore mouth (or 'mucositis') is one of the side-effects of chemotherapy, especially when given in high doses prior to a stem cell transplant. The lining of your mouth can become red and inflamed, which can sometimes result in extreme pain and discomfort. This is normally a temporary side-effect and your mouth should return to normal once you have recovered from your treatment.

## **Describing your pain**

In order for your doctor or nurse to treat your pain effectively, it is extremely important that you are honest about the level of pain that you are experiencing and the impact that it is having on your life.

You may be asked a range of questions to try to establish the exact nature of your pain – this helps to work out which treatment is most appropriate for you and also provides a baseline measure which is extremely helpful when trying to evaluate if the treatment you are prescribed is working.

Questions you may be asked include:

- Where do you feel your pain?
- When did it begin?
- What does it feel like? Is it sharp/dull/throbbing/burning?
- Does it prevent you from carrying out your daily activities?
- What makes it worse?
- What have you tried for pain relief?
- Is your 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.

You may also experience other symptoms associated with your pain. These can include nausea, headaches, dizziness, weakness, drowsiness, constipation and / or diarrhoea.

Pain can also have a huge emotional impact so it is important that you let your doctor, or nurse, know if you feel that living with pain is affecting your mood.

## **What are the treatments for pain?**

You do not have to put up with pain: there are many different treatment options available and most hospitals will have access to a specialised pain team which consists of a range of professionals who are experts at assessing and relieving pain.

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 you and must be regularly reviewed.

## **Medical treatments**

These can include:

### **Bisphosphonates**

Bisphosphonates 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 painkillers as well as reducing the likelihood of pathological fractures.

Bisphosphonate therapy is now recommended for all patients with myeloma requiring treatment, whether or not bone lesions are evident. The bisphosphonates that are used most commonly in myeloma are: ZOMETA® (Zoledronic Acid); AREDIA® (Pamidronate) and BONEFOS® (Sodium Clodronate).

### **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. Chemotherapy can be given either in tablet form (orally) or through an injection (intravenously). There are many different regimes used to treat myeloma including VAD, C-VAD, CTD, MP and C-VAMP.

If your myeloma responds to your chemotherapy treatment then you may find that you are able to stop taking or reduce strong painkillers once you have finished your treatment.

### **Radiotherapy**

Radiotherapy can be a very effective short-term treatment for relieving bone pain in localised areas as well as relieving pressure on the nerves or spinal cord. It is also used to treat solitary plasmacytomas.

### **Surgical Interventions**

Percutaneous vertebroplasty and balloon kyphoplasty are two new surgical procedures used for stabilising or reversing vertebral compression fractures. These procedures may offer considerable pain relief as well as strengthening the bones of the vertebrae.

In addition, balloon kyphoplasty can restore vertebral height which may have been lost due to the compression fracture.

### **Painkillers**

You may be prescribed painkilling medications (also known as 'analgesics') to try to get control of your pain. It is important that an individual approach is taken, so you may be prescribed several different painkillers.

As with any medication, most painkillers will have some side-effects. These can include constipation, nausea, loss of appetite and drowsiness. If caught early, most of these side-effects can be managed effectively. When used to treat severe pain, morphine (or any other strong painkiller) is not addictive.

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, carbamazepine or gabapentin may help relieve neuropathic pain. Steroids, particularly dexamethasone, may sometimes be used to relieve bone pain.

The over-the-counter non-steroidal anti-inflammatory group of painkillers (e.g. ibuprofen) are not recommended for use in myeloma as they can contribute to kidney damage.

## Painkillers commonly used in myeloma

| Class                                 | Examples  | Comments  |
|---------------------------------------|---|---|
| Simple non-opioid Analgesics          | Paracetamol   | Useful in mild to moderate pain.  |
| Non-steroidal anti-inflammatory drugs | Ibuprofen, voltarol   | Should be avoided or used only with caution.  |
| Weak opioids                          | Co-codamol, codeine, dihydrocodeine, tramadol   | Provide effective pain relief for moderate pain. Confusion and drowsiness may be experienced initially; can cause constipation; caution required in renal impairment. |
| Strong (natural) opioids              | Morphine – as liquid or tablets; can be converted to slow release preparations when daily requirements are established (e.g. MST)<br>Diamorphine – usually given by injection | Provide effective pain relief for moderate to severe pain. Side-effects as above.   |
| Synthetic opioids                     | Oxycodone – may be given orally<br>Fentanyl – given as slow release patches   | Provide effective pain relief for moderate to severe pain; some can be less toxic than natural opioids. Side-effects as above.  |

### Non-medical treatments

The following treatments may help you feel that you are getting more control over your pain and relieve some of the anxiety related to living with pain:

#### TENS machine

TENS (Transcutaneous Electrical Nerve Stimulator) 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. You can get a TENS machine from a physiotherapist or buy one from a large chemist.

#### Acupuncture

Acupuncture is part of traditional Chinese medicine and uses the balance of the body's own life force to restore wellbeing. Acupuncture needles are applied to areas where this flow has been blocked in order to restore balance and health. Acupuncture can be used to alleviate pain and to relax muscles.

It is important that you inform your doctor, or nurse, if you are receiving acupuncture and consult a qualified practitioner.

#### Gentle massage

Gentle massage can be used to relieve muscle pain and tension and can be both therapeutic and relaxing. Remember to tell the massage therapist that you have myeloma.

### **Hot and cold packs**

Hot water bottles and ice packs can be very effective as providing short-term pain relief. It is usually best to try to avoid applying them directly onto your skin and alternate between hot and cold.

### **Relaxation techniques**

Tense muscles can contribute to pain therefore learning relaxation techniques can not only ease your pain but can also help you cope with it better.

### **Correct positioning**

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

### **Self-help strategies**

Some things that you can do for yourself, to try to get control of your pain include:

#### **Asking for help when needed**

Do not be afraid to ask for help from those around you; most people are glad to be able to offer some assistance. If you think you need help around the home speak to your doctor or nurse who will be able to arrange for an occupational therapist to assess you. It may be possible for you to have aids fitted around your home (e.g. bath or shower seat) to make day to day living a bit easier.

#### **Taking painkillers regularly as prescribed**

Try to stick to the regimen that has been prescribed for you and do not wait until you are in pain before taking your painkillers; this will help your doctor assess if your current level of pain relief is working.

#### **Distraction therapy**

Some people find that watching TV 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**

Try to have some structure to your day whilst avoiding over-tiring yourself. Moderate gentle exercise (e.g. walking or swimming) can help strengthen your muscles and support your bones. It will also take your mind off your pain and can help lift your mood.

#### **Be honest with your doctor or nurse**

Do let your doctor, or nurse, know about the pain that you are experiencing, especially any new sites of pain or if it is increasing in intensity.

#### **Talking about your feelings**

Anxiety and stress can aggravate pain, so try to talk about your worries or concerns. If you would like to speak to a trained counsellor, your GP or local cancer centre should be able to organise this for you.

### **The future**

Pain control continues to be an important part of the treatment and management of myeloma. Research into new treatments for pain is ongoing.

## Further information and useful organisations

You will find a comprehensive listing of organisations able to provide you with support and information in relation to medical and palliative care, self-management and complementary therapies in *Myeloma – Your Essential Guide*.

Organisations working specifically with the issues of pain management include:

### **Pain Association (Scotland)**

**[www.chronicpaininfo.org](http://www.chronicpaininfo.org)**

0800 783 6059 (Monday–Friday, 9.30am–4pm)

Its helpline offers support to people with chronic pain. It runs pain management support groups across Scotland.

### **Pain Concern**

**[www.painconcern.org.uk](http://www.painconcern.org.uk)**

01620 822 572 (Weekdays 9am–5pm and Fridays 6.30pm–7.30pm)

Pain Concern provides a range of information about self-help and managing pain. Its helpline offers information, support and a listening ear.

## About this Infosheet

The information in this Infosheet is not meant to replace the advice of your medical team. They are the people to ask if you have questions about your individual situation. All Myeloma UK's publications are extensively reviewed by patients and healthcare professionals prior to publication.

## Other information available from Myeloma UK

Myeloma UK has a range of Essential Guides, Infoguides and Infosheets available, covering many areas of myeloma, its treatment and management. To order your free copies, contact the **Myeloma Infoline** on **0800 980 3332**. This information is also available 24/7 on our website at [www.myeloma.org.uk](http://www.myeloma.org.uk)

If you would like to talk to someone about any aspect of myeloma, its treatment and management, call the **Myeloma Infoline** on **0800 980 3332**. Your call will be answered by Myeloma Nurse Specialists who are supported by medical and scientific advisors. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK. From outside the UK, call +44 131 557 3332 (charged at normal rate).

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