

Pain and myeloma

Symptoms and
complications Infoguide

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You will find a definition of the terms highlighted in **bold** throughout this publication in the 'Medical terms explained' section on page 37

The quotes in this Infoguide are from myeloma patients and carers. Many of them are taken from 'The small things that make all the difference', a book of hints and tips written by people affected by myeloma for people affected by myeloma, available from Myeloma UK.

Disclaimer: The information in this Infoguide is not meant to replace the advice of your medical team. They are the best people to ask if you have questions about your individual situation.

This publication is intended for a UK audience.

It therefore may not provide relevant or accurate information for a non-UK setting.

Myeloma – an overview

Myeloma is a type of cancer arising from plasma cells that are normally found in the bone marrow. Plasma cells are a type of white blood cell which form part of the immune system.

Normal **plasma cells** produce different types of **antibodies** to help fight infection. In myeloma, the plasma cells become cancerous (sometimes called **malignant**) and release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. It is often through the measurement of paraprotein that myeloma is diagnosed and monitored.

Myeloma affects multiple places in the body (hence why it is sometimes referred to as ‘multiple myeloma’) where **bone marrow** is normally active, such as the bones of the spine, pelvis, rib cage and the areas around the shoulders and hips.

Most of the complications and symptoms of myeloma are caused by a build-up of the abnormal plasma cells (often called myeloma cells) in the bone marrow and the presence of paraprotein in the body.

Common problems in myeloma include bone pain, bone fractures, fatigue, frequent or recurrent infection and kidney damage.

Myeloma is highly treatable in the majority of cases. Treatment is aimed at controlling the disease, relieving the complications and symptoms it causes, and extending and improving the **quality of life**.

Treatment for myeloma is often most effective when two or more drugs, with different but complementary mechanisms of action, are given together. Treatment is usually given over a number of weeks which may or may not be followed by a rest period. This pattern constitutes one cycle of treatment and a series of treatment cycles is referred to as a course or line of treatment.

While there are many effective treatments for myeloma, unfortunately it is currently incurable. This means that even after successful treatment has

provided a period of **remission** or stable disease, the myeloma will return. This is called a **relapse**.

The causes of myeloma are not fully understood but it is believed to be caused by an interaction of both genetic and environmental factors.

Key facts

- There are approximately 5,800 people diagnosed with myeloma every year in the UK
- There are over 24,000 people living with myeloma in the UK at any one time
- Myeloma accounts for 15% of blood cancers and 2% of cancers generally
- Myeloma mostly affects people aged 65 and over but it has been diagnosed in people as young as 20

What is pain?

Pain is the most common symptom of myeloma affecting up to 80% of patients at some point. It is a sensation which causes discomfort or distress and is often a signal that the body is dealing with an injury or illness.

This signal is picked up by pain receptors in the nerve endings and is transmitted from the affected area to the brain. The brain then gathers the information and responds by telling your body to protect itself. Therefore, pain is part of a warning system to minimise potential harm to your body. Most pain resolves when the cause of the pain is removed and the body has healed.

While pain is most commonly linked to sensations caused by an illness, inflammation, surgery or physical injury, it is also linked to experiences influenced by memories, expectations and emotions. Pain can therefore have both physical and emotional components.

Pain is subjective and is very individual. What is bearable in one person may be intolerable in another person, even when the cause of the pain is similar. It is thought that a person's experience of pain may be

partly influenced by factors such as background and culture, genetics and gender.

Pain can have a significant impact on the quality of life of myeloma patients, especially if it is untreated or poorly managed. It can affect you physically, emotionally and socially. It can make it difficult to carry out daily tasks, and can also make it more challenging to cope with other symptoms and complications of myeloma. Pain can have a real impact on those closest to you, as well.

For all these reasons, managing and controlling pain properly is an important part of myeloma treatment.

Before deciding the best treatment for myeloma-related pain, your doctor or nurse will want to identify the nature and causes of the pain you have, and will try to understand its physical and emotional impacts.

Describing your pain

Pain can be described in a number of ways. Accurately describing your pain will help your healthcare team determine the best treatment for it.

Types of pain

There are many different types of pain and there are a number of different ways to describe it, including how severe the pain is, how long it has been going on for and where it is in the body.

How long the pain lasts can be described as:

- Acute pain – comes on quickly and lasts for a relatively short time
- Chronic pain – lasts for a longer time, does not go away, or comes back often

Where the pain comes from in the body can be described as:

- Somatic pain (also called musculo-skeletal pain) – from joints, muscle and bone
- Visceral pain – from the internal organs (such as the bowels)
- Neuropathic pain (nerve pain) – is caused by damage to, or pressure on, the nerves

Other ways pain can be described include:

- Breakthrough pain – a short-lived sharp spike of pain that overrides persistent controlled pain (background pain). It may happen unexpectedly or be triggered by something such as getting up after resting. It can happen in between regular doses of painkillers
- Total pain – this term is sometimes used and recognises that pain has emotional, social and spiritual elements as well as being physical, and that these different elements affect a patient's experience of pain

Discussing your pain with your healthcare team

Your healthcare team will ask you various questions about your pain. This will help them to work out how to manage and control your pain, and will give them a baseline to find out how well pain control treatments are working.

You may be asked questions including:

- Where do you feel your pain?
- When did it begin?
- What does it feel like? Is it sharp/dull/throbbing/burning?
- What effect does the pain have on your day-to-day activities?
- What have you noticed makes your pain worse or better? For example - heat, cold, moving around, or massaging the area?
- What have you tried for pain relief?
- Is your pain constant? If not, how many times a day (or week) does it occur?
- Does it occur at different times, i.e. is it worse in the morning or the evening?
- Do you have any other pain that may not be related to your myeloma?
- Has your pain recently changed?
- Do you feel in control of the pain or is it in control?

It is important for you to honestly and accurately describe your pain and the impact it is having on you so your healthcare team can help you as best as they can.

Some patients find that keeping a diary of their pain, over a few days, helps them to describe it more accurately. A diary may also help patients to pinpoint things that trigger their pain, and patterns of when the pain is worse. The free Myeloma UK Patient diary includes sections for recording symptoms including pain.

Order your free **Patient diary** from Myeloma UK by calling **0800 980 3332** or visiting **myeloma.org.uk**



You may be asked to rate your pain using a pain rating scale. This includes a number of questions about your pain and asks you to give your pain a numerical score (often between zero and ten with zero for no pain and ten for extreme pain). You can see an example of one in Appendix 1 on page 41.

Some doctors or nurses will use other pain rating tools such as body diagrams.

You may also have other symptoms alongside your pain. These can include nausea, headaches, dizziness, shortness of breath, weakness, drowsiness, increased sweating, **constipation** and/or **diarrhoea**. You should also discuss any of these symptoms with your doctor or nurse.

You will also be asked how your pain is affecting you emotionally (see page 8).

Psychological impact of pain

Pain not only affects the body, but it also has a significant psychological impact and affects how you feel emotionally. In particular, chronic pain can cause frustration, anxiety, anger, fear, poor concentration and sleep deprivation. In turn, these can affect not only how you cope with pain but affect the level of pain you have and how you deal with other aspects of life.

Pain that is not treated effectively can therefore lead to a vicious cycle of increased pain, **fatigue** and anxiety.

When your level of pain is assessed, it is likely that your doctor or nurse will ask you questions about how you are feeling generally.

They may ask you specific questions about the following:

- How much sleep you get each night and whether you feel tired or are fatigued
- If you feel anxious, scared or angry
- If you often feel down or depressed
- If you feel like you have the support that you need from family and friends

These questions will help your doctor and/or nurse to understand the extent pain is affecting you emotionally and provide the most effective pain treatment plan for you.

You may need additional psychological support if your pain is causing a significant emotional impact. For example, if it is affecting:

- Your relationships with others
- How well you are able to cope with other aspects of your life, for example managing your finances and household duties
- Your general outlook

In this case you may be helped by counselling or additional social support, and a pain assessment should identify any such additional needs you may have.

“ Be honest with your healthcare team and tell them how you’re feeling. They will be able to help you. ”

Causes of pain in myeloma

There are many potential causes of pain in myeloma. Pain can be a result of the myeloma itself or it can be caused by side effects of treatment.

This section describes some of the most common causes of pain in myeloma.

Myeloma bone disease

Myeloma bone disease is one of the most common and debilitating features of myeloma. Bone pain is a very common symptom of bone disease. Between 70 – 80% of patients have evidence of myeloma bone disease at the time of diagnosis and most patients will develop it at some point.

What is myeloma bone disease?

Healthy bone is not static, but it is in a constant state of remodelling which allows for minor areas of damage to be repaired and strengthened while maintaining the structure of the skeleton.

Two types of cells play an important role in the normal activity of bones. These are:

- **Osteoblasts** (cells which form new bone)
- **Osteoclasts** (cells which break down old bone)

Normally, the rate of bone formation and the rate of bone breakdown are equal, so that the bone mass remains the same. In myeloma, however, the myeloma cells in the bone marrow affect the surrounding bone, causing it to be broken down faster than it can be repaired.

This can lead to a number of problems including thinning of bone (**osteopenia**) and the eventual disappearance of pockets of bone producing holes called **lytic lesions**.

What causes the pain associated with myeloma bone disease?

Pain from myeloma bone disease may be a result of:

- Osteopenia and lytic lesions can cause a dull pain which may spread over a generalised area or may be more localised
- Bone fractures (caused by compression or thinning instead of injury or trauma) cause persistent severe pain which may be localised or radiate below the injury site. If a fracture occurs in a spinal bone (**vertebra**), the damaged bone may press on the spinal cord and may cause sharp shooting pain or numbness in the limbs. This is called **spinal cord compression** and should be treated as an emergency (see page 26)
- If there are several vertebral fractures, this can result in the collapse of the spinal column. This can feel like a dull achy pain, an acute agonising localised pain, or can be a shooting pain which travels up and down the leg
- If bones in the vertebrae collapse, a curve may develop in the back (**kyphosis**) which can cause loss of height. Kyphosis is often a cause of chronic back pain and mobility difficulties in myeloma patients. If the kyphosis is severe, it may put pressure on other areas of the body such as the rib cage and cause chest pains



For more information see the [Myeloma bone disease and bisphosphonates Infoguide](#) and the [Vertebral compression fractures in myeloma Infoguide](#) from Myeloma UK

Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves in the hands, feet, arms or legs i.e. in the **peripheral nervous system**. This can cause numbness, tingling, increased sensitivity and pain.

Peripheral neuropathy may be caused by the myeloma itself or by some of its treatments. Damage to the peripheral nervous system interferes with the messages being carried between the brain and the rest of the body. This causes the symptoms of peripheral neuropathy.

The pain caused by peripheral neuropathy is very individual to each patient. It is important that if you develop any (new) pain and/or sensations, you should tell your doctor or nurse as soon as you notice them.

What causes peripheral neuropathy in myeloma?

There are a number of potential causes of peripheral neuropathy in myeloma.

They include:

- Myeloma treatments, such as **thalidomide, bortezomib (Velcade®)** and vincristine (a **chemotherapy** drug). These can be toxic to nerve cells, particularly when given in high doses and/or for prolonged periods of time
- If you have previously received one of these treatments then neuropathy may be more likely with another new treatment
- The paraprotein produced by myeloma cells can be deposited on the nerves and damage them

Factors unrelated to myeloma such as diabetes, vitamin deficiency and a history of high alcohol consumption may also contribute to the symptoms of peripheral neuropathy. If you have one of these other conditions, then peripheral neuropathy related to myeloma or its treatment may be more problematic.

What kind of pain/sensation is associated with peripheral neuropathy?

The symptoms of peripheral neuropathy can vary from patient to patient and will depend on which nerves are affected – pain may not always be present. In myeloma, the hands and feet are the most commonly affected areas.

The sensations may include:

- Pain in various parts of the body – this can vary in intensity and is often described as ‘sharp’, ‘burning’, or ‘jabbing’
- ‘Pins and needles’ in the hands, arms, feet and legs – you may notice a tingling sensation which can start in your toes or the balls of your feet and travel up your legs. This sensation may also start in your fingers and work its way up your hands and arms
- Unusual sensations or an increased sensitivity to touch – often even the slightest touch can cause extreme discomfort. This is frequently worse during the night
- Altered sensations – such as a feeling of pain or heat when touching something cold
- Loss of sensation or numbness in the hands and/or feet
- Muscle cramps, weakness and tremors – this can interfere with your ability to perform everyday tasks

Symptoms of peripheral neuropathy often start at a low level but can increase and become more significant over time. Therefore, it is extremely important that you tell your doctor or nurse as soon as you develop any of these symptoms.

Peripheral neuropathy is often more easily and effectively treated if diagnosed early.

For more information see the **Peripheral neuropathy Infosheet** from Myeloma UK



Infection

Infection is a common complication of myeloma and therefore infection-related pain can also be common.

What causes infection in myeloma patients?

There are many different types of infection which may be caused by different types of bacteria, fungi and viruses. Infection is something that everyone has at some point in their lifetime. However, as a myeloma patient you are at an increased risk of getting an infection.

This is because myeloma cells crowd out the healthy blood cells in the bone marrow reducing the number of healthy blood cells, including white blood cells which play an important role in helping our body fight infection. Lower white blood cells is called **leukopenia**.

Some of the drugs used to treat myeloma such as thalidomide, bortezomib and **lenalidomide (Revlimid®)** can also reduce the number of neutrophils (a type of white blood which plays a key role in fighting infection). This is called **neutropenia**.

What type of pain is associated with infection?

Infection can occur in any part of the body and the pain associated with it can vary widely. The most commonly occurring infections and the type of pain associated with them include:

- Lung infections – such as pneumonia, can cause chest pains. The pain is usually located on one side of the chest and it is usually sharp and worsens with breathing and coughing
- Urinary tract infections – can cause pain when passing urine, which is felt as a burning sensation. Infections of this type can also cause cramping or pressure in the lower back or abdomen
- Skin infections – caused by the shingles virus can be very painful on and around the area of skin affected by the shingles rash. The skin becomes very sensitive to touch and the pain is usually a constant pain

- In addition, there may be intermittent sharp or stabbing pain which may, in some cases, continue up to a year after the shingles rash has disappeared. This is often referred to as **post-herpetic neuralgia**
- Mouth infections – causing mouth ulcers and sores in the inner cheek, inner lip, tongue, gumline and floor of the mouth, can cause pain or a burning sensation which is made worse by eating and drinking. **Oral thrush** caused by a fungal infection can also cause an uncomfortable burning sensation in the mouth and throat
- **Gastrointestinal** infections – can cause sudden, sharp abdominal pains and spasms

Fatigue

Fatigue is a condition that affects most, if not all, myeloma patients at some point and can be one of the most challenging complications of myeloma.

Fatigue is a feeling of extreme tiredness, lethargy or exhaustion. It is different from the everyday tiredness that comes with the demands of daily life, and is not relieved by sleep or rest. It can affect you physically, psychologically and emotionally.

How does fatigue cause pain?

Fatigue does not cause pain directly. However, fatigue can have a negative impact on pain. Unfortunately, fatigue and pain can be linked together in a vicious cycle if neither is addressed properly. For example, it can be difficult to sleep if you are in pain and a lack of sleep can be a contributing factor of fatigue. This can cause the pain you have to feel worse and make it harder to bear.

The management of fatigue is, therefore, an important factor to consider in the treatment of pain.

For more information see the **Fatigue Infoguide** from Myeloma UK



Side effects of anti-myeloma treatments

Treatments for myeloma can cause painful **side effects**.

- Diarrhoea, vomiting and constipation can be side effects of myeloma treatments, and can be associated with painful cramps
- Some myeloma treatments, such as high-dose melphalan which is given as part of **high-dose therapy** and **stem cell transplantation** (HDT-SCT) can cause the inside of the mouth and throat to blister. This is known as **mucositis**, and increases the risk of getting mouth infections
- Mucositis may also make your mouth and throat sore and eating, drinking and swallowing may become difficult for a while. In some cases, you may need **intravenous** fluids and/or nutrition until you are able to resume eating and drinking normally. You may also be given special mouth washes before food and drink, to numb the pain caused by eating or drinking

- Peripheral neuropathy (see page 11) and infections (see page 13) can also occur as side effects of myeloma treatments

Most side effects can be managed well and usually resolve once treatment is finished.

Pain due to tests, investigations and procedures

Myeloma patients undergo many tests, investigations and procedures. Some of these can cause pain.

Blood tests

You will have blood samples taken regularly, during treatment and while you are in remission. These should normally not be painful although they can be a little uncomfortable, and you may feel a brief sharp scratch as the needle is placed in your vein.

Blood tests are usually only painful if it is difficult to find a vein from which a sample can be taken.

Central line

You may have a **catheter** put into a vein in your chest for a period, particularly if you are having drug treatment by infusion. This is known as a **central line**, and the most common type is called a **Hickman® line**. The central line allows all your treatment drips/infusions to be given, and any blood samples taken, without putting a needle into your veins each time.

The catheter is inserted through a small cut in your chest and into the vein (see Figure 1). Inserting the line can be uncomfortable, but you will be given local **anaesthetic** in the area of skin where the line is inserted, to minimise the pain of this procedure. You may also feel some soreness in the area for a day or so after the central line has been inserted.

The most common cause of pain from a central line is if the insertion site becomes infected. You will be given advice about how to prevent infection. If you feel any pain around the insertion site, or notice redness or pus there, you should let your doctor or nurse know straight away.



For more information about central lines see the **High-dose therapy and autologous stem cell transplantation Infoguide** from Myeloma UK

Bone marrow tests

You will have bone marrow tests as part of the process of diagnosing whether you have myeloma. There are two types, normally done at the same time. Bone marrow aspirate is where a small amount of liquid bone marrow is removed, and bone marrow biopsy (trephine biopsy) is where a small narrow core of solid tissue is taken from the bone marrow.

The bone marrow samples are usually taken from the **pelvic bone** (see Figure 2).

Before the procedure, the skin is cleaned and local anaesthetic is injected into the skin in the area. For the aspirate, a needle is passed through the skin and into the bone, and a sample of liquid bone marrow is drawn up through a syringe. For the trephine biopsy the aspirate needle is replaced with a slightly larger one, which is inserted into

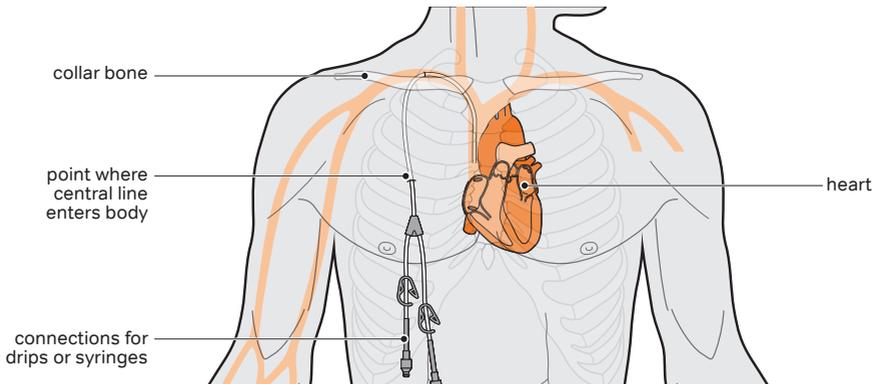


Figure 1. Insertion of a Hickman line

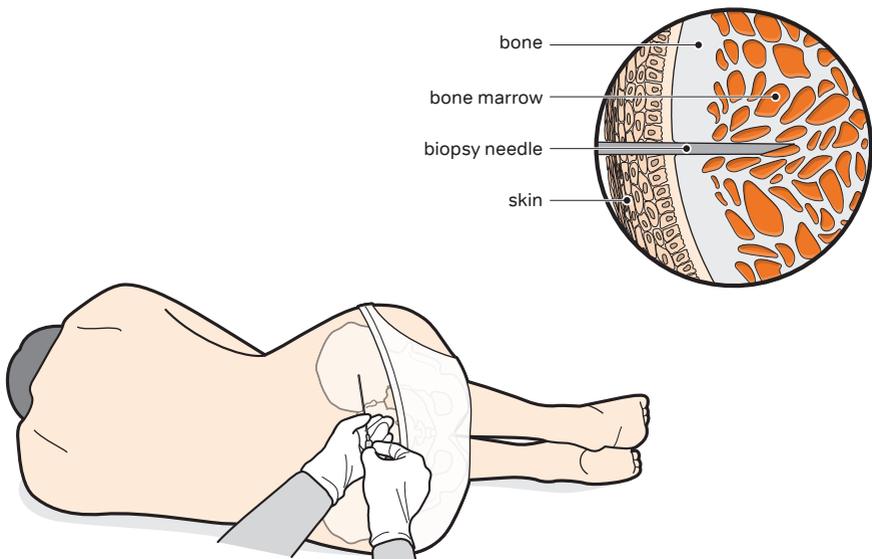


Figure 2. Bone marrow sample being taken from the pelvic bone

the bone, and turned while being inserted further into the bone marrow, until a core of bone marrow can be carefully removed. The procedures last only a few minutes.

You may experience pain at points during these procedures, which may be a pulling and pushing sensation, or a sudden sharp pain. Depending on the circumstances, you may be offered a **sedative**.

There may be some discomfort and bruising for a few days after the biopsy, for which normal painkillers should help.

If you have pain from myeloma bone disease that makes it uncomfortable for you to lie still in particular positions, mention this to the doctor or nurse doing the biopsy, and they may be able to suggest alternative positions for you.

For more information about bone marrow tests see the **Tests and investigations Infoguide** from Myeloma UK



Radiotherapy

Radiotherapy is the use of high-energy radiation (usually X-rays) to kill cancer cells. Radiotherapy is most often used to treat small areas of myeloma bone disease that are causing bone pain (see page 25).

Although radiotherapy is used to improve bone pain, it can also cause mild side effects including pain for a while afterwards. This can include:

- Sensitivity of skin – the skin at the site of treatment can become red and sore (similar to sunburn), and the skin on the other side of the body (where the radiation leaves the body) can be affected too. The radiotherapy staff will give you self-help advice on how to care for your skin after radiotherapy treatment, to minimise any problems
- Mouth sores – these can sometimes happen if the radiotherapy is in your upper body. You will be given advice on how to manage this side effect

For more information see the **Radiotherapy Infosheet** from Myeloma UK



Treatment of pain

How your pain is treated will depend on its cause and how it is affecting you. If your healthcare team are unable to remove the cause of your pain, they will aim to help you manage it in the best way possible.

There are many different options available to treat pain, and certain treatments work better on particular causes or types of pain. Pain control must be tailored specifically to you and it must be reviewed on a regular basis. Not all pain treatments will work in every patient and it is often only through a trial and error approach that your doctor will find the best pain relief for you. If needed, your healthcare team will have access to specialists who are experts in pain management.

Some of the most commonly used treatments for pain management for myeloma patients are described in the following sections.

Anti-myeloma treatments

Myeloma-related pain is often relieved by treatment of the myeloma itself. Anti-myeloma treatments (drugs which kill myeloma cells) are, therefore, a key part of pain management.

If your myeloma responds to treatment then it may be possible to reduce or stop any painkillers you are taking.

Painkillers

Different painkillers are used to treat different levels of pain (mild, moderate and severe).

There are many different types of painkiller available, with different actions and different side effects. Pain relief is very individual, with different painkillers suiting different patients at different times. The painkillers most commonly used in myeloma are listed in Table 1 on page 24.

Simple non-opioid painkillers include drugs such as paracetamol, and are used to treat mild to moderate pain. However, **non-steroidal anti-inflammatory drugs (NSAIDs)** like ibuprofen, diclofenac and aspirin

should not be used in myeloma, because they can worsen kidney damage.

Opioid painkillers are a group of different drugs in the chemical family of morphine. Weak opioids are used for mild to moderate pain that is not controlled by non-opioid painkillers. Strong opioids are used for moderate to severe pain. They can be very effective for treating some types of pain but they need to be used carefully to make sure there are no unnecessary side effects.

Strong opioids include morphine, diamorphine, oxycodone, high-dose tramadol and fentanyl. If a patient cannot tolerate the side effects of one opioid their healthcare team may try switching to another one. Morphine is usually tried first unless there are specific reasons why it cannot be given.

In treatment of pain other than cancer, there is a concern about using opioids for too long.

However, in cancer such as myeloma, opioids have an important place in long-term management of pain which cannot be controlled in other ways.

How are painkillers used?

As there is such a wide range of painkillers available, it is important to find the one that works best for you. This may need a trial and error approach as no two patients are alike and the pain they have may be different. In addition, some painkillers may not be suitable for certain patients due to complications or side effects that can be caused or made worse by the painkillers.

Usually, your doctor will start with a low dose of a particular painkiller first, and increase the dose until pain is controlled but the level of side effects is acceptable. If this can't be achieved they will then prescribe you a different or stronger painkiller.

Pain is more difficult to control once it has become severe. For this reason it is important to take your prescribed painkillers at the intervals recommended by your doctor, and not wait until you are experiencing severe pain.

Forms of painkillers

Painkillers come in different forms which are absorbed into the body in different ways. These include tablets, liquids, lollipops (which allow the drug to be absorbed through the mouth lining), skin patches, nasal sprays, suppositories (treatments that are inserted into the rectum or back-passage), or injections. Injections may be given under the skin (**subcutaneous** injections) or into a vein (intravenous injections). The form you will be given depends on the specific painkiller and your own circumstances.

Painkillers vary in how quickly they enter your system, and the same painkiller can be made up in a form that enters your system quickly or slowly. Immediate release painkillers go into your system quickly and control pain quickly. When you are started on a new painkiller you are likely to be given it in an immediate release form. Once the right dose has been found and your pain is under control, your doctor may change the drug to a modified

release form. These are absorbed gradually, and provide a more steady level of the drug in your system.

If you are on modified release painkillers for severe pain, you will also be given a supply of quicker acting painkillers to use in case of breakthrough pain. For example, if you have severe breakthrough pain when you stand up or walk, you may be advised to take an immediate release painkiller 30 minutes before getting out of bed in the morning.

Side effects of painkillers

Opioid painkillers, especially strong opioids, can cause a number of side effects. The most common are:

- Constipation – all opioids, particularly the stronger ones, cause constipation, but a lot of patients can be treated easily with **laxatives**. All patients treated with strong opioids will be given laxatives. You should tell your doctor if you are finding constipation a problem, as it is easier to deal with before it has lasted for too long
- Nausea and sickness – if this occurs it is usually at the start of treatment. With some opioids, you will be given an anti-sickness drug at the start
- Drowsiness – this is more common with strong opioids, and at the start of treatment, but often wears off as treatment is continued. It may affect your ability to drive or operate machinery. If you have cancer and your treatment causes side effects that could affect your driving, you are required by law to inform the DVLA – see www.gov.uk/cancer-and-driving
- Increased sweating – this can happen with some opioids
- Effects on breathing – this can occur especially at the start of some strong opioid treatments, or if too much is taken. Care will be taken at the start of a new opioid treatment, especially if you have other breathing problems
- Symptoms such as confusion, hallucinations, muscle twitching or breathing problems, may be a sign that you are taking too much opioid

It is important to tell your doctor if you are experiencing side effects after starting a new painkiller, even if the painkiller is reducing your pain. It may be possible to reduce the dose, give you treatments to control the side effect (such as laxatives or anti-sickness drugs), or try an alternative treatment which will maintain the same (or better) level of pain control with less side effects. Use the Myeloma UK Patient diary to record any side effects you are experiencing – that way you will remember the details during clinic appointments.

Other drug treatments used for pain relief

Other drugs that are not normally used as painkillers may also be helpful in certain circumstances. In particular, drugs such as **amitriptyline** and **gabapentin** are used to help relieve pain in peripheral neuropathy. As with most treatments, these drugs can cause their own side effects and may not be suitable for every patient.



For more information see the **Peripheral neuropathy Infosheet** from Myeloma UK

Drug class	Name of painkillers	Form given and comments
Simple non-opioid painkillers used for mild to moderate pain	Paracetamol	Usually tablets, capsules or tablets which can be dissolved and given as a liquid
Weak opioids used for mild to moderate pain not controlled by simple non-opioids	Co-codamol, codeine, dihydrocodeine, low-dose tramadol	Usually tablets or capsules
Strong opioids used for moderate to severe pain	Morphine	Given as liquid or tablets; may be given in slow release form when pain control has been stabilised. Also given in other forms including injection
	Diamorphine	Usually by injection
	Oxycodone	Given as liquid, tablets or capsules
	High-dose tramadol	Given as tablets, capsules, liquid or slow release tablets/capsules
	Fentanyl	Given as slow release patches, tablets, lozenges or as a nasal spray
	High-dose buprenorphine	Given as skin patches. Can cause sickness at the start of treatment – patients are given anti-sickness drugs for the first week

Table 1. Painkillers commonly used for the treatment of pain in myeloma

Bisphosphonates

Bisphosphonates are a specific group of drugs that help to protect and strengthen bones and therefore minimise the extent of, or prevent, bone damage.

As well as reducing the likelihood of pathological fractures, bisphosphonates can also relieve bone pain and may reduce the need for strong painkillers.

Bisphosphonate treatment is recommended for all myeloma patients requiring anti-myeloma treatment, whether or not myeloma bone disease is evident. The bisphosphonates that are most commonly used in myeloma are: zoledronic acid (Zometa[®]), disodium pamidronate (Aredia[®]) and sodium clodronate (Bonafos[®] and Loron[®]).

National guidelines now recommend zoledronic acid as the bisphosphonate of choice for all patients with active myeloma.

However, you and your doctor may consider that another bisphosphonate is more appropriate for you.



For more information see the **Myeloma bone disease and bisphosphonates Infoguide** from Myeloma UK

Radiotherapy

Targeted radiotherapy can be helpful for patients with localised bone pain. Radiotherapy kills off the myeloma cells, which in turn reduces bone pain.

Radiotherapy is also effective in relieving the pain caused by a deposit of myeloma cells pressing on the spinal cord, often known as malignant spinal cord compression. Usually, the first sign of spinal cord compression is unexplained back pain that gradually gets worse. The pain may feel like a tight band around the chest or abdomen and can radiate down to the buttocks and legs. Other symptoms of spinal cord compression include incontinence (bladder or bowels), limb weakness or limb numbness.

Spinal cord compression is a medical emergency and you should seek urgent medical attention if you have any symptoms. Radiotherapy treatment should be started as soon as possible, to prevent permanent damage to the spinal cord, which can result in paralysis.

For more information see the **Radiotherapy Infosheet** and the **Vertical compression fractures in myeloma Infoguide** from Myeloma UK

Surgical procedures

Two surgical procedures that treat vertebral fractures, known as **percutaneous vertebroplasty** and **balloon kyphoplasty**, relieve back pain as well as strengthening the vertebrae (bones in the spine).

These procedures are not suitable for all patients. Doctors select patients very carefully, taking into consideration the location of the pain, the type of vertebral fracture and the time elapsed since the fracture occurred. You will not be considered if you do not have adequate white blood cell counts or

if you are prone to bleeding. Usually, more conventional treatments for your back pain will be tried first.

For more information see the **Vertebral compression fractures in myeloma Infoguide** from Myeloma UK

Skin creams

Creams applied to the skin (topical treatments) can be useful for painful skin areas caused by peripheral neuropathy. Capsaicin cream (containing an ingredient derived from chillies) is sometimes useful for 'cold' neuropathic symptoms, and menthol creams (containing an extract from mint) for neuropathic pain that produces 'hot' sensations.

Spinal injections

A spinal injection is an injection of painkiller into the area round the spinal cord. It is also called an epidural or spinal anaesthetic. The aim of a spinal injection is to 'turn off' pain signals. Doctors may use spinal injections to treat cancer pain that is not well controlled by painkillers given in other ways.

Non-medical treatments

There are also many non-medical strategies which are sometimes used instead of, or alongside, medical treatments to help treat or relieve your pain. Not all of these treatments are suitable for all patients, and you should ask your healthcare team for advice before starting a new treatment.

TENS machine

Transcutaneous electrical nerve stimulation (TENS) machines deliver small electrical pulses to the body via electrodes placed on the skin. The electrical impulses can reduce the pain signals going to the spinal cord and the brain. They may also stimulate the nerves reaching the brain to signal to the body to release its own painkillers, hormones called **endorphins**. TENS machines are not suitable for everyone, and some patients should not use them. You should ask your healthcare team for advice. More information from www.nhs.uk.

Acupuncture

Acupuncture is a treatment derived from ancient Chinese medicine. Fine needles are inserted at certain sites in the body for therapeutic or preventative purposes.

Acupuncture is used by many people to relieve pain but you should keep in mind that you are at an increased risk of infection because of your myeloma and its treatment, so you should always inform your doctor or nurse about any complementary therapies that you are considering.

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 and that forceful massage could damage your bones.

Hot and cold compression packs

Hot water bottles and ice packs can be very effective in providing short-term pain relief. It is best not to apply them directly on your skin, and you may need to alternate between hot and cold packs.

Relaxation techniques

Meditation, visualisation, mindfulness, relaxation or a combination of these can be helpful in relieving pain.

Correct positioning

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

“ Hot water bottles and wheat bags were my best friend. ”

The palliative care team

Many myeloma patients will have their pain managed by their myeloma team and GP. However, if your pain is severe and difficult to control, you may be referred to a palliative care team. Hospice teams can also be involved in managing pain control for myeloma patients.

What does the palliative care team do?

The palliative care team can be made up of doctors, specialist nurses, psychologists, physiotherapists and occupational therapists – the exact members of the team may differ from hospital to hospital. They provide specialist care in symptom control and can give advice and care for patients either at the hospital or in the home, or as part of hospice care.

The palliative care team can help you to manage your pain and advise on which treatments you should be given. Palliative care teams provide

holistic care. This means that as well as symptom control they also provide psychological, social and emotional care, and support for your family and friends.

There is a misconception that the palliative care team are there purely to provide end of life care.

This is one aspect of their role, but they also provide specialist care in pain management and symptom control for patients at all stages of their cancer or illness. You can be referred to a palliative care team, by your doctor, at any time.

What is hospice care?

The aim of hospice care is to improve the lives of people who have an incurable illness. Like palliative care, hospices are not just concerned with care at the end of life, but can have a role at any time during a patient's illness. Hospice care is holistic, meaning it aims to look after the whole range of needs a patient and their family have. Hospice care may take place at home, as well as in a hospice itself.

You may use hospice services at different times during your illness depending on your needs. This might be when help is needed to control your pain symptoms, or for example when your family or carers have a break from care responsibilities. Patients may be referred for hospice care by their GP or healthcare team, and patients can also contact hospices directly themselves.

Getting the pain management you need

In most cases pain in myeloma can be relieved, even when myeloma is at an advanced stage.

Poorly controlled, severe chronic pain is very debilitating and can have a significant impact. The earlier pain is treated the more effective the treatment usually is, and pain that is controlled as well as possible will enable you to live better with your myeloma.

However, taking painkillers, especially strong opioids, can cause concerns to patients, including worries about getting addicted to the painkiller or needing increasing amounts of it, or concerns that the painkillers will make them drowsy or 'out of it'.

Addiction to strong painkillers

Addiction happens when people get a psychological 'high' from a drug, and have cravings that make them want to take it again. However, if you have been prescribed strong opioids because you need them to control pain from advanced cancer, and are taking them as prescribed, then addiction to them is very unlikely. If you have had previous issues

with drug misuse, speak to your healthcare team who will discuss the best options for you in your own situation.

Tolerance to strong painkillers

Tolerance means that your body gets used to a drug over time and you need to take more and more of it to get the same amount of pain relief. This is unlikely to happen when you are taking strong painkillers for cancer pain, but if it does your doctor will adjust the dose or may try a different form of painkiller.

It may be necessary to adjust the dose of your painkiller from time to time, because your pain has got worse or better. This is different from tolerance. If your painkiller is not working as well as it did, talk to your healthcare team about adjusting the dose or trying a different painkiller. They will monitor you carefully for side effects if your painkiller dose is increased, or will try a different painkiller if you are having problems with side effects.

Strong opioids can cause physical symptoms if you stop taking them suddenly after you have been taking them for some time. These symptoms are called withdrawal symptoms, and can include tiredness, sweating and muscle pain. Your doctor will advise you about how to reduce the dose of your opioid gradually.

It is important not to stop an opioid, or change how much you take, without speaking to your healthcare team first.

Drowsiness and other side effects of strong painkillers

Drowsiness and problems with concentration can happen with strong painkillers, especially when you start a new painkiller or when your dose has been increased, but these effects are likely to improve after a time. If drowsiness is more severe or long-lasting, your healthcare team may:

- Reduce the dose of your painkiller if your pain is well controlled
- Consider changing the painkiller you are taking
- Seek specialist advice from a palliative care team or pain specialist (see page 29)

If you have cancer and your treatment causes side effects that could affect your driving, you are required by law to inform the DVLA – see www.gov.uk/cancer-and-driving

See page 22 for more information about side effects of painkillers.

Talking to your healthcare team about pain symptoms

Some patients are reluctant to raise issues about pain symptoms, because they feel as if they are complaining, or because there does not seem to be enough time in a busy appointment. They may also worry that pain is a sign that their myeloma is getting worse, and therefore they may not want to raise the subject.

However, if your pain is not well controlled it is important that you ask about it so that you can get the best pain relief possible, and that you ask to be referred to a pain specialist if you feel you are not getting the help you need.

Living with pain

It can be very difficult to live with pain and you may need a lot of help and support. It is important to remember that the extent of your pain may not always be obvious to family, friends, doctors and nurses. In order for them to know that you are in pain, you have to tell them.

Your doctor or nurse will try to reduce your pain by medical, non-medical or surgical interventions but there are also some things that you can do yourself to try to control your pain and to cope with it. Some self-help tips and strategies are listed below.

Ask for help when needed

Do not be afraid to ask for help from those around you; most family members and friends are glad to be able to offer some assistance. If you think you need help around the home, speak to your doctor or nurse – they 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 easier.

Take painkillers regularly as prescribed

Stick to the dose and schedule of painkillers that you have been prescribed and do not wait until you are in pain before taking your painkillers as they will not be as effective. If you find that your painkillers are not effective, go back to your doctor or nurse and try something else.

Distraction therapy

Some patients find that watching TV, listening to the radio or engaging in a hobby can help to take 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 overtiring 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.

Being honest with your doctor or nurse

Be honest about any pain that you have, especially if it is getting worse, or if it is in a new place in your body. Remember your doctor and nurse are there to help you.

Talking about your feelings

Anxiety and stress can make pain worse, so try to talk about your worries or concerns with people who are close to you or with your doctor. If you would like to speak to a trained counsellor, your GP or hospital should be able to organise this for you.

“ Explore all options if you are still experiencing pain – weekly one hour pilates sessions have really helped me. ”

Top 10 tips for coping with pain

- 1** Ask for help when needed

- 2** Take each day as it comes and have patience

- 3** Try to keep mobile and active

- 4** Try different pain relief until you find one that suits you

- 5** Find a hobby to help take your mind off the pain

- 6** Seek help from a variety of sources

- 7** Ask to be referred to a specialist service such as pain management clinic, palliative care service or hospice service

- 8** Listen to your body and go at your own pace

- 9** Don't suffer in silence, let people know how they can help

- 10** Try to keep a positive mental attitude

Medical terms explained

Amitriptyline: An antidepressant drug that can be used to treat neuropathic pain.

Anaesthetic: A type of drug used to temporarily reduce or take away sensation so that otherwise painful procedures or surgery can be performed. A general anaesthetic makes the patient unconscious and therefore unaware of what is happening. A local anaesthetic numbs the part of the body that would otherwise feel pain.

Antibodies (immunoglobulins): Also known as immunoglobulins, antibodies are proteins found in the blood which are produced by cells of the immune system, called plasma cells. Their function is to bind to substances in the body that are recognised as foreign such as bacteria and viruses. They enable other cells of the immune system to destroy and remove them, thereby helping to fight infection.

Balloon kyphoplasty: A procedure used to repair/ stabilise a compression fracture in one or more vertebrae and to relieve pain. It is a similar procedure to percutaneous vertebroplasty but in addition to stabilising the fracture, aims to reshape and restore the height of the damaged vertebra. It involves an inflatable balloon tamp being inserted in the vertebrae and inflated to create a space. The tamp is removed and the space is filled with bone cement.

Bone marrow: The soft, spongy tissue in the centre of bones that produces white blood cells, red blood cells and platelets.

Bortezomib (Velcade®): A type of drug called a proteasome inhibitor.

Catheter: A tube that is placed in a blood vessel to provide a pathway for drugs or nutrients.

Central line: A catheter (tube) which is inserted under the skin in the chest into a large vein just above the heart. It can be kept in for several months and is used to administer treatments and to take blood samples.

The most common type is called a Hickman® line and a central venous access device.

Chemotherapy: Treatment with potent drugs intended to kill cancer cells. Chemotherapy drugs can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

Constipation: Condition that can mean that you're not passing stools (poo) as often as is normal for you, or you're unable to completely empty your bowel. It can also cause your stools to be hard and lumpy.

Diarrhoea: Condition that means passing softer, more liquid or more frequent stools (poo) than is normal for you.

Endorphins: Chemicals produced by the body that serve to suppress pain.

Fatigue: A feeling of being exceptionally tired, lethargic or exhausted all or most of the time. It does not result from activity or exertion and is not relieved by rest or sleep.

Gabapentin: An anti-epileptic drug that can be used to treat neuropathic pain.

Gastrointestinal: Refers collectively to the stomach, small and large intestine.

Hickman® catheter/line: The most common type of central line (see glossary).

High-dose therapy: High-dose chemotherapy given intravenously, usually via a Hickman® or PICC line, prior to patients receiving healthy stem cells as part of the transplantation procedure.

Intravenous: Into a vein.

Kyphosis: An abnormal curvature of the spine.

Laxative: A type of drug used to treat constipation.

Lenalidomide (Revlimid®): An immunomodulatory drug which is given orally.

Leukopenia: A reduced level of white blood cell. White blood cells are important for fighting bacterial infection.

Lytic lesions: A damaged area of a bone that shows up as a dark spot on an X-ray. Lytic lesions look like holes in the bone and are evidence that the bone is being weakened.

Malignant: Cancerous cells which have the ability to invade and destroy tissue.

Mucositis: Pain and inflammation of the lining of the mouth and/or gastrointestinal tract.

Neutropenia: A reduced level of neutrophils, a type of white blood cell important for fighting bacterial infection.

Non-steroidal anti-inflammatory drug (NSAID): Drugs used to prevent or treat pain which do not contain steroids

Oral thrush: An infection of yeast fungus in the lining of the mouth.

Osteoblast: Cells which form new bone.

Osteoclast: Cells which break down old bone.

Osteopenia: Thinning or weakening of the bone.

Paraprotein: An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease.

Pelvic bone: The bones which connect the trunk and the legs.

Percutaneous vertebroplasty: A procedure used to repair/ stabilise a compression fracture in one or more vertebrae and to relieve pain. It involves injecting bone cement into the vertebra to stabilise and strengthen it.

Peripheral nervous system: Consists of the nerves outside the brain and spinal cord.

Peripheral neuropathy: Damage to the nerves that make up the peripheral nervous system causing pain, tingling and altered sensation.

Physiotherapist: A healthcare professional who treats patients with physical difficulties resulting from injury, illness, disability or ageing. They work with patients to identify and improve their movement and function.

Plasma cells: A type of white blood cell that produces antibodies (immunoglobulins) to fight infection.

Post-herpetic neuralgia: Nerve pain which persists in patients who have had shingles, after the shingles rash has disappeared.

Quality of life: A term that refers to a person's level of comfort, enjoyment, and ability to pursue daily activities. It is a measure of an overall sense of well-being.

Relapse: The point where disease returns or becomes more active after a period of remission or plateau (often referred to as stable disease).

Remission: The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Sedative: A type of drug which has a calming effect to help reduce or relieve anxiety, stress or excitement, and is often used to induce sleep.

Side effects: The undesired effects caused by a drug or treatment, for example fatigue or nausea.

Spinal cord compression: The term used to describe pressure on the spinal cord. It can be caused by a collapsed vertebra or by the growth of a plasmacytoma within the spinal canal.

Stem cell transplantation: The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

Steroid: A group of hormonal substances produced by the body. They are also produced synthetically and used to treat many conditions.

Subcutaneous: under the skin.

Thalidomide: An immunomodulatory drug.

Vertebra: A bone which forms part of the spine.

Appendix 1:

Example of a pain rating scale

How intense is your pain now?										
0	1	2	3	4	5	6	7	8	9	10
no pain								extreme pain		

How intense was your pain on average last week?										
0	1	2	3	4	5	6	7	8	9	10
no pain								extreme pain		

How distressing is your pain now?										
0	1	2	3	4	5	6	7	8	9	10
not at all distressing								extremely distressing		

How distressing was your pain on average last week?										
0	1	2	3	4	5	6	7	8	9	10
not at all distressing								extremely distressing		

How much does your pain interfere with your normal everyday activities?										
0	1	2	3	4	5	6	7	8	9	10
does not interfere								interferes completely		

If you have had treatment for your pain, how much has this relieved (taken away) the pain?										
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
no relief								complete relief		

Pain rating scale based on one produced by the British Pain Society (see page 7).

Useful organisations

Carers UK

www.carersuk.org

0808 808 7777

Provides advice, information and support for carers.

Citizens Advice

www.citizensadvice.org.uk

England: 03444 111 444

Wales: 03444 77 20 20

Scotland: call your local office

Northern Ireland: use Advice NI, visit adviceni.net

Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support

www.macmillan.org.uk

0808 808 0000

Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's

www.maggiescentres.org

0300 123 1801

Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind

www.mind.org.uk

0300 123 3393

Provides advice and support to empower anyone experiencing mental health problems.

NHS 111 Service

www.nhs.uk/111

111

Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

We're here for everything a diagnosis of myeloma brings



Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.



Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**



Learn about myeloma from experts and meet other patients at our **Patient and Family Myeloma Infodays**.



Order or download our **information publications**, which cover all aspects of myeloma - call **0800 980 3332** or visit **myeloma.org.uk**



Join your nearest **Myeloma Support Group** to meet up and talk to other people face to face.



Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.



Watch **Myeloma TV**, videos about myeloma presented by experts, patients and family members.



Use the **Discussion Forum** for the opportunity to share experiences and advice about living with myeloma.



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We need your help

Thanks to our generous supporters we are able to provide information and support to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.

Myeloma UK receives no government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a single donation or setting up a Direct Debit**

Online at myeloma.org.uk/donate

Over the phone **0131 557 3332**

Or by posting a cheque payable to **Myeloma UK** to:

Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG

- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness
- **Leaving a gift in your will** – legacies are an important source of income for Myeloma UK and help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments

However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 557 3332** or email fundraising@myeloma.org.uk

“

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do.

”

Judy Dewinter – President, Myeloma UK

We appreciate your feedback. Please fill in a short online survey about our patient information at myeloma.org.uk/pifeedback or email any comments to myelomauk@myeloma.org.uk

For a list of references used to develop our resources, visit myeloma.org.uk/references



Symptoms and complications Infoguide: Pain and myeloma



We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on

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Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**

Myeloma UK

22 Logie Mill, Beaverbank Business Park,
Edinburgh EH7 4HG

 0131 557 3332

 myelomauk@myeloma.org.uk

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