

# Peripheral neuropathy

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## Symptoms and complications Infosheet

**This Infosheet explains what peripheral neuropathy is, what causes it in myeloma patients, how it is treated and some tips for self-management.**

### What is 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 and feet.

### What is the peripheral nervous system?

Your nervous system is made up of two parts:

- **The central nervous system (CNS)** which consists of the brain and the spinal cord
- **The peripheral nervous system (PNS)** which consists of all the nerves outside the brain and spinal cord. The peripheral nervous system includes nerves in your face, arms, legs, chest and some nerves in your skull

The nerves act as communicators within the body and are made up of lots of specialised cells called neurons. Neurons pass on information about sensations and movement via electrical impulses.

There are different types of neurons:

- **Motor neurons** transmit impulses from the brain to the muscles throughout the body. In response to these impulses, muscles contract to cause movement
- **Sensory neurons** transmit impulses to the brain from all around the body. Sensory neurons enable you to feel sensations such as pain and touch as well as sensing where your body is in relation to your surroundings

When the nerves within the peripheral nervous system become damaged the messages that they carry between the brain and the rest of the body can become distorted or interrupted. This is what happens in peripheral neuropathy, causing varying symptoms such as altered sensation, tingling, numbness or pain. The pain caused by peripheral neuropathy is referred to as neuropathic pain and is highly individual to each patient. If you develop any new pain or sensations, it is important that you discuss them with your doctor or nurse as soon as you notice them.

## What causes peripheral neuropathy in myeloma?

Some myeloma patients have symptoms of peripheral neuropathy at diagnosis. Quite a large number of myeloma patients develop some peripheral neuropathy as a later complication of myeloma or as a result of treatment. The causes of peripheral neuropathy in myeloma are varied.

They can include:

- **Treatments**, such as thalidomide, bortezomib (Velcade®) and vincristine (part of the VAD treatment combination), which can all damage the nerve cells, particularly when given in high doses. Myeloma treatments are the most common cause of peripheral neuropathy in myeloma. If you have previously received one of these treatments then you may be at greater risk of neuropathy occurring with subsequent treatments
- **The paraprotein produced by the myeloma cells**, which can be deposited on nerve tissue and damage the nerve cells. High levels of paraprotein can also lead to thickening of the blood, called hyperviscosity. This may reduce the circulation of the blood and lead to symptoms of peripheral neuropathy
- **Shingles** (a common viral infection), which can cause neuropathic pain and changes in the sensation of the affected areas
- In some cases, **kidney damage** may cause peripheral neuropathy due to fluids and waste products accumulating in the body
- **Diabetes, vitamin deficiency or a history of high alcohol consumption** may also cause or worsen peripheral neuropathy

## What are the symptoms of peripheral neuropathy?

The symptoms of peripheral neuropathy can vary from person to person. They will depend on which nerves are affected. In myeloma, the hands and feet are the most commonly affected areas.

Common symptoms include:

- **Pain** – this can vary in intensity and is often described as ‘sharp’, ‘burning’ or ‘jabbing’. This is referred to as neuropathic pain
- **‘Pins and needles’** – 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 often worse at night time
- **Altered sensation** – such as a feeling of pain or heat when touching something cold
- **Numbness** – in the hands or feet
- **Muscle cramps, weakness and tremor** – this can interfere with carrying out everyday tasks

- **Lack of co-ordination or sense of position** – it may sometimes seem that your body is not doing what you want it to. You may also find your sense of where things are in your surroundings can become distorted
- **Loss of dexterity** – carrying out everyday tasks that need intricate movements of the fingers and hands, such as doing up buttons, may become more difficult

Symptoms of peripheral neuropathy often start off gradually but can become more problematic over time. Severe peripheral neuropathy can impact your quality of life, your sleep, and your ability to carry out normal activities. In some cases permanent nerve damage can result. Therefore, it is extremely important that you inform your healthcare team as soon as you start to experience any of the above symptoms. Peripheral neuropathy is often more manageable if diagnosed early.



**Tell your healthcare team as soon as you have symptoms of peripheral neuropathy, no matter how mild they are.**

You may have a test to confirm that you have peripheral neuropathy. This test will also check which nerves are affected and how much damage there is. The test is called a nerve conduction study. For the test, electrodes to stimulate your nerves will be attached to your skin. You may feel a tapping or tingling sensation but this should not be too uncomfortable.

### **What are the treatments for peripheral neuropathy?**

Managing peripheral neuropathy involves treating the symptoms, and at the same time identifying the cause.

If the cause of the peripheral neuropathy is related to the myeloma itself, it may improve as your myeloma is treated.

If peripheral neuropathy is caused by your myeloma treatment, your doctor will discuss with you the available options:

- Continuing with your treatment while keeping a close eye on your symptoms and treating them as needed
- Changing the dosing schedule or the way your treatment is given
- Lowering the dose
- Stopping the treatment for a while until your symptoms have improved
- Sometimes it may be necessary to stop the myeloma treatment you are on completely, in order to prevent long-term damage. Your doctor will discuss alternative treatment options with you

In the majority of patients, peripheral neuropathy symptoms improve after the drug causing them is stopped, although this may not happen straight away.

For peripheral neuropathy due to bortezomib, switching to giving it by subcutaneous injection (under the skin) instead of intravenous infusion (into a vein) can help.

Bortezomib is less likely to cause peripheral neuropathy when it is given in this way, and if it does occur it is likely to be less severe. Bortezomib is now increasingly given subcutaneously.

Controlling symptoms of peripheral neuropathy is very individual, and what works for each patient may vary. Your symptoms may be improved through a variety of the following treatments.

### **Pain-relieving drugs**

Neuropathic pain caused by peripheral neuropathy does not usually respond well to ordinary painkillers such as paracetamol. Instead, it is treated with specific drugs that are known to help with this type of pain. Some of these drugs are also used in the treatment of other conditions, but being given them does not mean your doctor thinks you have these other conditions.

The drugs most commonly used for neuropathic pain are:

- Gabapentin and pregabalin (also used to treat epilepsy)
- Amitriptyline (also used to treat depression)
- Duloxetine (used to treat diabetic peripheral neuropathy, and sometimes also neuropathy that has other causes)
- Carbamazepine (also used to treat epilepsy)
- Strong painkillers (opioids) such as tramadol, but usually only if your neuropathic pain symptoms are severe
- Local anaesthetic injections or patches (such as lidocaine) can be effective in blocking the pain from the damaged nerves

You may also be referred to a pain clinic or a palliative care team. Palliative care teams specialise in managing symptoms including pain.

If the treatment you have been given does not work, speak to your healthcare team who will be able to try something else. This may be a different dosage or type of drug. You may need to try several different options to find something to help manage your symptoms.

## Other treatments

A range of other treatments may help with peripheral neuropathy symptoms. You should discuss these with your healthcare team to make sure they are suitable for you. They include:

- **Transcutaneous electrical nerve stimulation (TENS).**

Some patients find TENS machines helpful. They work by delivering tiny electrical impulses to specific nerve pathways through small electrodes placed on your skin. TENS machines are not suitable for everyone and you should ask for advice before using one

- **“Cooling” creams** (such as menthol) or **“warming” creams** (such as capsaicin cream) may be helpful to treat a problem area, particularly if the neuropathy is making the affected area feel hot or cold. Capsaicin is the substance that makes chillies hot, so you should wash your hands carefully after using it, and not use it on broken skin

- **Complementary therapies** such as acupuncture, reflexology and gentle massage may help to relieve some of your symptoms. Ask if you can be referred to the complementary therapy service at your local hospital

- **Vitamin supplements** such as vitamin B complex, folic acid, magnesium and alpha-lipoic acid are sometimes considered helpful in managing the symptoms of neuropathy

- **Relaxation techniques** such as meditation, visualisation, relaxation or a combination of these can be helpful in reducing muscle tension, which may be contributing to your pain



For more information about management of pain see the **Pain and myeloma Infoguide** from Myeloma UK.

## Tips for self-management

There are many things that you can do to make living with peripheral neuropathy a bit easier. These include:

- Taking care of your hands and feet – wear well-fitting protective shoes; keep hands and feet warm. Some patients find that getting cold makes their symptoms worse, and judging when your hands and feet are cold can be difficult if they are numb
- Using caution when getting into baths or showers – check the temperature of the water first
- Taking regular gentle exercise – this will help to keep your muscles toned and will improve circulation. Ask your healthcare team to advise before starting any new form of exercise
- Stopping smoking – ask your GP or practice nurse for advice and local support groups
- Eating a well-balanced diet – try to eat a diet that includes all the essential vitamins and minerals

- Avoiding falls – try to reduce the risks in your own home by making sure hallways and stairs are well lit and free from clutter. Be aware that if you have numbness in your toes, or loss of co-ordination, you are more likely to trip
- Using adaptations to help with everyday tasks – ask your healthcare team about getting aids and adaptations, such as hand rails, fitted in your home. An occupational therapist can do an assessment and suggest adaptations that would help
- Adopting good posture – avoid sitting with legs crossed for long periods of time as this can put extra pressure on your nerves
- Making use of warmth and cold – ice packs or hot water bottles may provide some short-term relief. Wrap them in a towel before placing onto the skin and it may be necessary to alternate between warmth and cold

If you drive, you are required by law to inform the DVLA if you have peripheral neuropathy. You will need to complete the DVLA CN1 form which can be downloaded from [www.gov.uk/peripheral-neuropathy-and-driving](http://www.gov.uk/peripheral-neuropathy-and-driving), or call the DVLA on 0300 790 6806.

## Key points

- Peripheral neuropathy is damage caused to the nerves around the body
- It can have several causes in myeloma patients, including some of the drugs used to treat myeloma, and the myeloma itself
- It can cause symptoms such as ‘pins and needles’, numbness or pain
- It is important to report symptoms as soon as possible, as peripheral neuropathy is easier to treat early
- Management includes pain-relieving drugs and topical creams
- Other treatments such as complementary therapies may help with symptoms
- If you have peripheral neuropathy caused by your myeloma treatment, your healthcare team may in some cases consider reducing the dose, changing the way the drug is given or switching to a different drug
- There are many things you can do to make living with peripheral neuropathy easier, such as keeping your feet warm, taking regular gentle exercise and taking precautions around the house to minimize the risk of falls

## About this Infosheet

The information in this Infosheet is not meant to replace the advice of your healthcare team. They are the people to ask if you have questions about your individual situation.

For a list of references used to develop our resources, visit [myeloma.org.uk/references](https://myeloma.org.uk/references)

We value your feedback about our patient information.

For a short online survey go to [myeloma.org.uk/pifeedback](https://myeloma.org.uk/pifeedback) or email comments to [patientinfo@myeloma.org.uk](mailto:patientinfo@myeloma.org.uk)

## Other information available from Myeloma UK

Myeloma UK has a range of publications available covering all aspects of myeloma, its treatment and management. Download or order them from [myeloma.org.uk/publications](https://myeloma.org.uk/publications)

To talk to one of our Myeloma Information Specialists about any aspect of myeloma, call our Myeloma Infoline on **0800 980 3332** or **1800 937 773** from Ireland.

The Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK and Ireland.

Information and support about myeloma is also available around the clock at [myeloma.org.uk](https://myeloma.org.uk)

# Notes

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## 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

 **0800 980 3332**

Email Ask the Nurse at

 **[AskTheNurse@myeloma.org.uk](mailto:AskTheNurse@myeloma.org.uk)**

Visit our website at

 **[myeloma.org.uk](http://myeloma.org.uk)**



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