Peripheral neuropathy

Symptoms and complications Infosheet

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

What is peripheral neuropathy?

Neuropathy means 'damage to nerves'. Peripheral neuropathy means damage to the nerves that communicate information such as pain and touch, or that sense our position and control movement. Damage can cause pain, tingling and altered sensation.

What nerves are affected in peripheral neuropathy?

Our nervous system controls our actions, our responses to information around us, and the functioning of internal organs. It is made up of two parts:

- The brain and the spinal cord, called the central nervous system
- The nerves around the body including in the face, arms, legs and chest, called the peripheral nervous system

The nerves send messages around the body, and are made up of many specialised cells called neurons. Neurons pass on information about sensations and movement.

The peripheral nervous system uses different types of neurons:

- Motor neurons send information from the brain to muscles throughout the body. This causes muscles to contract, creating movement
- Sensory neurons send information from all around the body back to the brain. This is how you feel sensations such as pain and touch. It also helps you to sense where your body is in relation to your surroundings

When motor or sensory neurons 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.

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
- Tingling – this can start in your toes or the balls of your feet and travel up your legs. Tingling may also start in your fingers and work its way up your hands and arms
- 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 the nerve damage can be permanent, but it is often more manageable if diagnosed early.

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

Testing for peripheral neuropathy

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 that 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 causes peripheral neuropathy in myeloma?

It is possible to have symptoms of peripheral neuropathy at the time of diagnosis. It is more common to develop symptoms later on, after a diagnosis. This can be as a complication of the myeloma itself 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). These can damage the nerve cells, particularly when given in high doses. Other treatments, including elranatamab (Elrexfio®), selinexor (Nexpovio®), and teclistamab (Tecvayli®) can also cause peripheral neuropathy through nerve damage. If you have previously received one of these treatments then you may be at greater risk of neuropathy occurring with future treatments

- Paraprotein produced by myeloma cells. This can be deposited on the nerves and damage them. High levels of paraprotein can 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
- Kidney damage. This can sometimes cause peripheral neuropathy due to fluids and waste products accumulating in the body
- Diabetes, vitamin deficiency or a history of high alcohol consumption. These can also cause or worsen peripheral neuropathy
- Spinal compression fractures can happen as a serious complication of myeloma bone disease. They can put pressure on the spinal cord and damage the nerves. This can cause back pain, numbness, weakness or tingling in the arms or legs

Call 999 immediately if you think you are developing a spinal cord compression fracture. These fractures are a medical emergency.

For more information about spinal cord compression see the **Managing spinal fractures in myeloma Infoguide** from Myeloma UK.

What are the treatments for peripheral neuropathy?

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

If the peripheral neuropathy is caused by the myeloma itself, it may improve as your myeloma is treated.

If peripheral neuropathy is caused by your myeloma treatment, your healthcare team will discuss with you the available options. Lowering the dose of the treatment thought to be causing it, changing the dosing schedule or the way treatment is given, or stopping treatment for a time, may improve symptoms. This does not always lead to an immediate reduction in symptoms but it is usually possible to see an improvement over a number of weeks or months.

Bortezomib is usually given as a subcutaneous injection (under the skin) instead of an intravenous infusion (into a vein). It 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.

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.

Sometimes it may be necessary to stop a treatment permanently to prevent long-term nerve damage. If this is necessary, your health care team will discuss alternative treatment options with you.

Pain-relieving medicines

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

Your healthcare team will decide which medicines are most appropriate based on the source of your pain. The medicines 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

Non-steroidal anti-inflammatory medicines (such as ibuprofen and high-dose aspirin) should not be used in myeloma because they can worsen kidney damage.

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

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 treatment. 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) – TENS machines 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 your healthcare team for advice before using one. For more information see the NHS website at **nhs.uk/tests-and-treatments/transcutaneous-electrical-nerve-stimulation-tens/**
- "Cooling" creams (such as menthol) or "warming" creams (such as capsaicin cream) – these 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 reflexology, gentle massage, and aromatherapy may help to relieve some of your symptoms. Ask if you can be referred to the complementary therapy service at your local hospital
- 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

Vitamin supplements such as vitamin B complex, folic acid, magnesium and alpha-lipoic acid are sometimes considered helpful in managing symptoms of neuropathy. However, there is no firm evidence to support their use.

Supplements or herbal medicines that have not been prescribed by your healthcare team may cause harm when taken alongside your prescribed treatment.

You must speak to your healthcare team before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so.

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:

- Making sure you take your painkillers regularly as prescribed – don't wait until your pain gets worse
- 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

- Reducing your fall risk at home – make 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
- Distraction therapy – such as watching TV, doing a hobby or chatting to a friend – these can sometimes help by taking your mind off neuropathy symptoms for a time

Having peripheral neuropathy affects each person differently. It is normal to feel isolated or frustrated because your symptoms change your lifestyle. Help is available through your healthcare team, palliative care teams and centres such as Maggie's (**maggies.org**).

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 **gov.uk/peripheral-neuropathy-and-driving**, or call the DVLA on **0300 790 6806**.

Key points

- Peripheral neuropathy is damage to the nerves that send information such as pain and touch to the brain
- Symptoms include pain, tingling, numbness and lack of co-ordination
- Possible causes include certain myeloma treatments, paraprotein deposits damaging the nerves, and other factors such as damage from kidney problems
- It is important to report symptoms as soon as possible, as peripheral neuropathy is easier to treat early
- Management includes pain-relieving medicines 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 treatment is given or switching to a different treatment
- 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 minimise the risk of falls

Notes

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**

We value your feedback about our patient information. For a short online survey go to **myeloma.org.uk/pifeedback** or email comments to **patientinfo@myeloma.org.uk**

Other information available from Myeloma UK

Myeloma UK has a range of information booklets available covering all aspects of myeloma and related conditions. Download or order them from **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**

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MyelomaUK

We're here for everything a diagnosis of myeloma brings

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

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0800 980 3332

Email Ask the Nurse at
AskTheNurse@myeloma.org.uk

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Myeloma UK
22 Logie Mill, Beaverbank Business Park,
Edinburgh EH7 4HG
0131 557 3332
myelomauk@myeloma.org.uk
Registered Charity No: SC026116

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