

Peripheral neuropathy

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** – found within the peripheral nervous system, these 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 occurs 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 and/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?

Up to 14% of myeloma patients are estimated to have symptoms of peripheral neuropathy at diagnosis, but approximately 80% of patients develop some degree of it 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. 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 area(s)
- 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 contribute to the symptoms of peripheral neuropathy

What are the symptoms of peripheral neuropathy?

The symptoms of peripheral neuropathy can vary from person to person and 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’
- **‘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 and/ or feet
 - **Muscle cramps, weakness and tremor** – this can interfere with your ability to perform everyday tasks
 - **Lack of co-ordination and/ 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** – performing everyday tasks that require 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. Therefore, it is extremely

important that you inform your doctor or nurse as soon as you start to experience any of the above symptoms. Peripheral neuropathy is often more manageable if diagnosed early.

You may have a nerve conduction study carried out to confirm the diagnosis of peripheral neuropathy, identify which nerves are affected and evaluate the extent of the damage. The test involves having electrodes attached to your skin which stimulate your nerves. You may feel a tapping or tingling sensation but this shouldn't be too uncomfortable.

What are the treatments for peripheral neuropathy?

The key to the management of peripheral neuropathy is to eliminate or reduce the cause at the same time as treating the symptoms that occur.

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 treatment, lowering the dose of the drug thought to be responsible or discontinuing it for a period of time may relieve symptoms. However, this does not always lead to an immediate reduction in symptoms.

Sometimes it will be necessary to stop the treatment permanently in order to prevent long-term damage. Your doctor will discuss alternative treatment options with you.

For bortezomib-related peripheral neuropathy, changing the route of administration from intravenous infusion (into a vein) to subcutaneous injection (under the skin) significantly reduces the occurrence and severity of neuropathy. Bortezomib is now increasingly given as a subcutaneous injection.

An individual approach is necessary to try and control the symptoms of peripheral neuropathy. They may be improved through a variety of the following treatments.

Pain relieving medications

Neuropathic pain caused by peripheral neuropathy may respond best to:

- Anti-depressant drugs (such as amitriptyline)
- Anti-epileptic drugs (such as gabapentin or carbamazepine)

Other treatments

A range of other treatments may help relieve your symptoms including:

- Opioid drugs (such as codeine or morphine)

- Quinine tablets or drinking tonic water (which contains quinine) to help with cramps
- Local anaesthetic injections or patches (such as lignocaine) can be effective in blocking the pain from the damaged nerves
- Transcutaneous electrical nerve stimulation (TENS) machine can sometimes help reduce your level of pain by delivering tiny electrical impulses to specific nerve pathways through small electrodes placed on your skin

Complementary therapies

Acupuncture, reflexology and gentle massage may help to relieve some of your symptoms.

Vitamin supplements

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

As there is no firm research to support the use of these therapies and supplements, it is essential to consult a qualified practitioner.

You should also talk to your doctor or nurse to ensure that the therapies or supplements are safe to use and that they do not interact with any of your myeloma treatments.

Relaxation techniques

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.

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
- 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
- Stopping smoking – ask your GP or practice nurse for advice and/or local support
- 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
- Using adaptations to help with everyday tasks – ask your doctor or nurse about getting aids and

adaptations, such as hand rails, fitted in your home

- Adopting good posture – avoid sitting with legs crossed for long periods of time as this can put extra pressure on your nerves
- Make 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 now 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 the DVLA website or call the DVLA on 0300 790 6806.

Future directions

Doctors are currently looking at the best ways of using available treatments to try and reduce the risk of peripheral neuropathy where possible. The increasing use of subcutaneous bortezomib, for example, follows evidence that this route of administration is as effective as intravenous injections, but crucially reduces the occurrence and severity of peripheral neuropathy.

It is hoped that newer drugs used to treat myeloma will cause less

peripheral neuropathy, for example the newer proteasome inhibitors carfilzomib (Kyprolis®) and ixazomib (Ninlaro®) have been shown to cause less peripheral neuropathy than bortezomib.

As more is learnt about how to prevent, treat and manage peripheral neuropathy, it is hoped this complication will become less common and more manageable.

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.

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

To give feedback about this publication, email myelomauk@myeloma.org.uk

Other information available from Myeloma UK

Myeloma UK has a range of publications available covering all areas of myeloma, its treatment and management.

To order your free copies or 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 www.myeloma.org.uk

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