

# Peripheral neuropathy

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**This Infosheet explains what the peripheral nervous system is, what peripheral neuropathy is, what causes it in AL amyloidosis patients, its symptoms and treatments and 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 AL amyloidosis the nerves that are most commonly affected are those of the hands, lower legs and feet.

## 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, including nerves in your face, arms and hands, legs and feet, 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. These neurons pass on information about sensations and movement via electrical impulses.

There are several types of neurons, including:

- **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 nerves within the peripheral nervous system become damaged, the messages that they carry to and from the brain and the rest of the body can become distorted or interrupted. This results in 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 AL amyloidosis, the hands, lower legs 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 frequently 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** – which can interfere with your ability to perform everyday tasks

- **Lack of coordination and/or sense of position** – it may sometimes seem that your body is not doing what you want it to do. You may also find your sense of where things are in your surroundings can become distorted
- **Loss of dexterity** – performing simple 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. They can also be highly individual to each patient. It is important that if you develop any new pain and/or sensations you discuss them with your doctor or nurse as soon as you notice them. Peripheral neuropathy is often more manageable if diagnosed early.

### What causes peripheral neuropathy in AL amyloidosis?

Around a fifth of patients are affected by some degree of peripheral neuropathy when diagnosed with AL amyloidosis. The causes of peripheral neuropathy in AL amyloidosis are varied. They can include:

- **Amyloid deposits** in the nerves, which cause damage to the nerve cells
- **Treatments** such as thalidomide and Velcade® (bortezomib), which can damage the nerve cells, particularly when given in higher doses. If you have peripheral neuropathy before you start treatment, you may be more likely to develop treatment-related neuropathy
- **Shingles** (a common viral infection), which can cause neuropathic pain (nerve 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 treatments for peripheral neuropathy?

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

If the peripheral neuropathy is caused by amyloid deposition in the nerves, then improvement may occur with treatment for the AL amyloidosis. If amyloid deposition is already affecting your nerves you may be more likely to develop treatment-related neuropathy. Your doctor will take this into account in deciding what treatment to recommend. For example, the drug Revlimid® (lenalidomide) is less likely to cause neuropathy than thalidomide, so a Revlimid-based drug combination may be recommended.

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 alleviate symptoms. This does not always lead to an immediate reduction in symptoms but it is possible to see an improvement over a number of weeks or months.

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

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.

An individual approach is necessary to try to control the symptoms of peripheral neuropathy. This can include:

### **Pain-relieving medications**

Neuropathic (nerve) pain caused by peripheral neuropathy may respond best to:

- Anti-depressant drugs – such as amitriptyline
- Anti-epileptic drugs – such as Neurontin™ (gabapentin), Lyrica™ (pregabalin) or Tegretol™ (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) may 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 alphas-lipoic acid are sometimes considered helpful in managing the symptoms of neuropathy. However, as there is no firm research to support the use of these vitamin supplements, you should talk to your doctor before using any to ensure they are safe to use and do not interact with any of your other treatments for AL amyloidosis
- Relaxation techniques - techniques such as meditation, visualisation, relaxation or a combination of these may be helpful in reducing muscle tension, which can contribute to pain

## Some 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** – 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

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.

### **In summary**

It is widely recognised that peripheral neuropathy can be a serious problem and, if left untreated, it can have a huge impact on your quality of life. In order to prevent it becoming a long-term or permanent problem it is important that you report it to your doctor or nurse so that they can find ways to minimise it.

Doctors are currently looking at the best ways of using available treatments to try to reduce the risk of peripheral neuropathy where possible. The increasing use of subcutaneous Velcade, 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. 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. All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

## Other information available from Myeloma UK

Myeloma UK provides a wide range of information covering all aspects of the treatment and management of AL amyloidosis.

For a full publication list visit [www.myeloma.org.uk/publications](http://www.myeloma.org.uk/publications)

To order your free copies contact Myeloma UK. Our information is also available to download at [www.myeloma.org.uk](http://www.myeloma.org.uk)

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

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

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