

Peripheral neuropathy

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.

What is the peripheral nervous system?

The peripheral nervous system (PNS) is the part of the nervous system that consists of all the nerves outside the brain and spinal

cord, including nerves in your face, arms, hands, legs, feet, chest, and some nerves in your skull.

The peripheral nervous system is made up of two parts: the somatic nervous system and the autonomic nervous system. The somatic nervous system controls your voluntary movements and relays sensory information, such as pain, touch and where you are in relation to your surroundings, to your brain. It is these nerves that are involved in

peripheral neuropathy.

For more information about the autonomic nervous system and autonomic neuropathy see the [Autonomic neuropathy Infosheet](#) from Myeloma UK

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. In some cases the nerve damage can be permanent but it 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 bortezomib (Velcade®), 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 lenalidomide (Revlimid®) is less likely to cause neuropathy than thalidomide, so a lenalidomide-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 bortezomib-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. Bortezomib is now usually given as a subcutaneous

injection.

Sometimes it will be necessary to stop the treatment permanently 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:

Prescribed pain relief

Neuropathic (nerve) pain caused by peripheral neuropathy may be relieved by:

- Anti-depressant drugs – such as duloxetine or amitriptyline
- Anti-epileptic drugs – such as gabapentin, pregabalin or carbamazepine
- Opioid drugs (such as codeine or morphine)
- Local anaesthetic injections or patches (such as lignocaine) can be effective in blocking the pain from the damaged nerves

Other treatments

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

- Quinine tablets or drinking tonic water (which contains quinine) to help with cramps
- 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 alpha-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

Tips for self-management

There are many things that you can do to make living with peripheral neuropathy a bit easier, including:

- 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.

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. It is important that you report it to your doctor or nurse so that they can find ways to minimise it to prevent it becoming a long-term or permanent problem.

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 covering all aspects of AL amyloidosis, its treatment and management. To download any of these publications go to www.myeloma.org.uk/publications

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call the Myeloma UK 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 AL amyloidosis is also available around the clock at www.myeloma.org.uk/amyloidosis

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