

Peripheral neuropathy

Peripheral neuropathy is damage to the nerves of your peripheral nervous system (network of nerves outside of the brain and spinal cord). Peripheral neuropathy can be a side effect of treatment for lymphoma. Occasionally, it can be a symptom of the lymphoma itself.

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What is peripheral neuropathy?

Peripheral neuropathy is temporary or permanent damage to the nerves of the peripheral nervous system. The nervous system works a bit like a network of electrical wires. The receptors and nerves within it pick up and carry signals and messages between different parts of your body.

Peripheral neuropathy causes too much or too little nerve activity and disrupts communication between the nerves in your body.

The peripheral nervous system is made up of the:

- **sensory nervous system**, which carries information about the sensations your skin and joints feel (such as heat, pain and touch), through the spinal cord and to the brain
- **autonomic nervous system**, which carries messages to and from your internal organs (for example about blood pressure, heart rate and the need to urinate)
- **motor nervous system**, which carries messages from the brain, down the spinal cord and to the muscles to make them move.

For the majority of people, symptoms improve over time, although this can take months or even years. For some people, symptoms continue permanently. There is a higher likelihood of this with more severe symptoms of peripheral neuropathy.

What are the symptoms of peripheral neuropathy?

Symptoms of peripheral neuropathy depend on which nerves are affected: **sensory**, **autonomic** or **motor**. Sensory nerves are most commonly affected.

Sensory neuropathy

Peripheral neuropathy that affects the sensory nervous system is known as 'sensory neuropathy'. The most common symptoms of sensory neuropathy are:

- pins and needles, numbness or a burning sensation, often in the hands or feet
- pain
- increased sensitivity to touch
- heightened or lowered sensitivity to very hot or very cold temperatures
- unexplained sensations (for example, feeling as though you have something in your shoe)
- not being sure about the exact position of your joints when you aren't looking at them.

Tasks that need fine movements, like doing up buttons, tying shoelaces or opening jars, can be difficult.

Symptoms that start in your hands and feet might travel further up into your arms or legs if the neuropathy becomes more severe.

Autonomic neuropathy

Peripheral neuropathy that affects the autonomic nervous system is known as 'autonomic neuropathy'. The most common symptoms of autonomic neuropathy are:

- light-headedness or dizziness when you stand up
- **constipation**
- abdominal (tummy) bloating
- feeling unable to wait to pass urine
- impotence in men.

These symptoms may affect your **day-to-day life** and your **relationships**. Your doctor can give you advice about how to manage your symptoms.

Motor neuropathy

Peripheral neuropathy that affects the motor nervous system is known as 'motor neuropathy'. The most common symptoms of motor neuropathy are:

- muscle twitches, cramps or pains
- muscle weakness, which can make tasks like writing, carrying things and climbing stairs difficult
- 'restless legs' (an urge to move your legs).

Tell your medical team as soon as possible if you have symptoms of peripheral neuropathy.

Why do people with lymphoma get peripheral neuropathy?

You might have peripheral neuropathy as a:

- side effect of treatment, for example **chemotherapy** or **radiotherapy**
- symptom of the lymphoma itself
- sign of another condition or illness.

Side effect of lymphoma treatment

Some treatments for lymphoma can cause nerve damage. This is the most common reason for peripheral neuropathy in people with lymphoma.

Whether you develop peripheral neuropathy depends on which drugs you are treated with and the dosage you have.

The drugs most likely to cause peripheral neuropathy are:

- vinca alkaloids (a group of chemotherapy drugs) including vincristine (Oncovin®) and vinblastine (included in the ABVD **chemotherapy regimen**)
- platinum-based drugs, including cisplatin, oxaliplatin and carboplatin
- other drugs such as **bortezomib** (Velcade®), thalidomide and **brentixumab vedotin** (Adcetris®).

If peripheral neuropathy is likely to be a side effect of the drugs recommended for you, your doctor should discuss this with you before you begin treatment.

Chemotherapy-induced peripheral neuropathy (CIPN) tends to affect sensory nerves more often than motor nerves or autonomic nerves. You might have only mild symptoms such as tingling in your hands and feet. Severe symptoms are less common.

When symptoms start depends on the type of chemotherapy you have; however, symptoms often occur after a few **cycles** (courses) of chemotherapy. Occasionally, symptoms may get worse or even start only once your treatment has finished. This is sometimes called 'coasting'.

Symptom of lymphoma

The lymphoma itself can cause peripheral neuropathy. This may happen:

- if paraproteins (chemicals produced by some lymphomas), stick to nerves and damage them. This is quite common, particularly in people with **Waldenström's macroglobulinaemia** (WM), half of whom are affected by peripheral neuropathy
- if lymphoma cells spread into nerves, compress (push up against) them or grow around the tiny blood vessels that supply the nerves. This is rare.

Some people in **remission** wonder if a worsening of symptoms of peripheral neuropathy mean that their lymphoma is relapsing (coming back). This is very unlikely to be the case.

Another condition or illness

You might already have another condition that can cause peripheral neuropathy, such as **diabetes** or **low vitamin B12 levels**.

Drinking a lot of alcohol over a long period of time can also cause nerve damage.

Having both lymphoma and another condition that can cause nerve damage increases your risk of developing peripheral neuropathy. Your medical team consider this when they plan your treatment.

How is peripheral neuropathy diagnosed?

Usually, peripheral neuropathy is diagnosed by asking questions about how your symptoms affect your day-to-day activities.

You are likely to also have a physical examination, which might include:

- checking the reflexes in your ankles, knees and wrists (automatic movements in response to being tapped)
- assessing your sense of touch
- looking at your balance and coordination (for example, whether you are able to walk in a straight line)
- seeing whether you can tell where parts of your body are when you have your eyes closed
- checking how your blood pressure changes when you move from lying to standing – a drop could indicate damage to your autonomic nerves.

Motor neuropathy is not a very common side effect of treatment for lymphoma. However, if you do experience such symptoms, you might be referred to a neurologist (doctor specialising in disorders of the nervous system) to check for nerve damage. Your neurologist may do a nerve conduction test and an electromyography (EMG) test. Usually, these tests are done in the same appointment.

You must tell the DVLA if you are diagnosed with peripheral neuropathy.

Nerve conduction test

A nerve conduction test involves attaching electrodes (small devices that carry tiny electrical impulses) to your skin. Your neurologist checks how quickly and effectively your nerves carry the electrical impulses. Very slow or weak signals could be a sign of peripheral neuropathy.

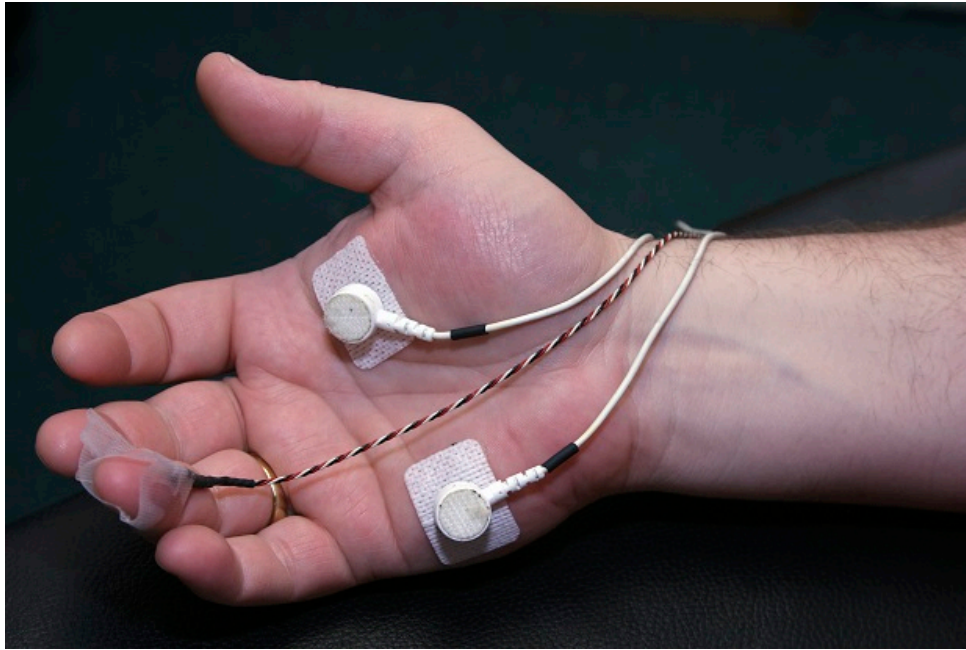


Figure: A nerve conduction test

Electromyography (EMG) test

An EMG test involves having a small needle put into a muscle. The needle measures the responses of the muscle to the electrical signals. Little or no response could be a sign of peripheral neuropathy.

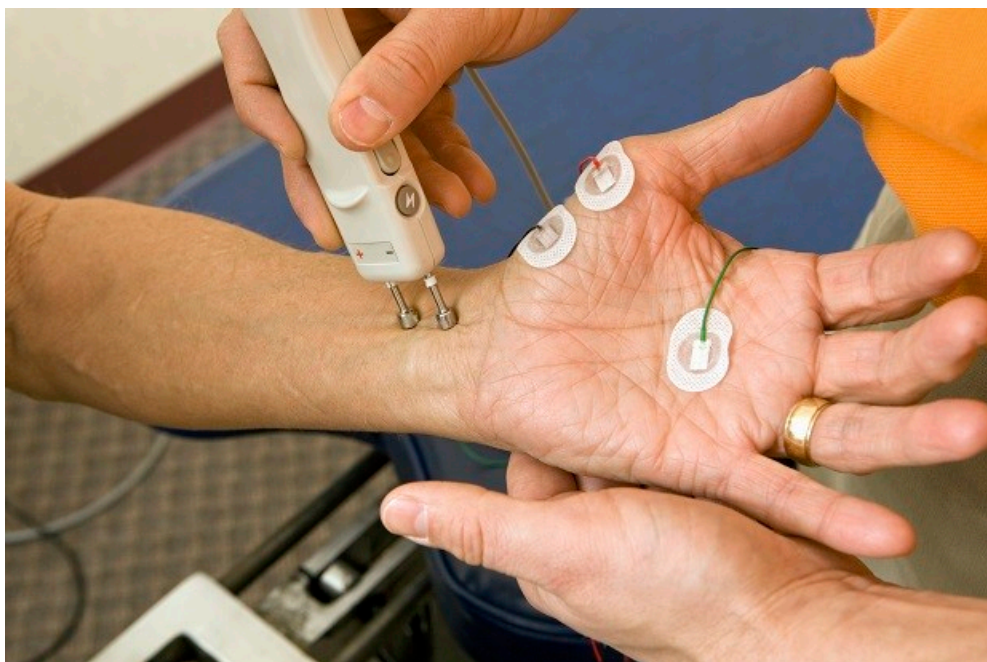


Figure: An electromyography (EMG) test

How is peripheral neuropathy treated?

Tell your medical team as soon as possible if you have symptoms of peripheral neuropathy. At the moment, there is no way to reverse nerve damage. The best course of action is to try to prevent further nerve damage, which is often more successful the earlier nerve damage is found.

Symptoms often start to go away once you finish treatment for lymphoma. It may, however, be weeks or even months before you notice any improvement. For some people, the symptoms never go away completely. With **Waldenström's macroglobulinaemia**, neuropathy often starts to improve once you begin treatment for the lymphoma.

Occasionally, with chemotherapy-induced peripheral neuropathy, symptoms worsen after finishing chemotherapy.

If your treatment causes or worsens peripheral neuropathy, your medical team might reduce the dose or switch you to a different treatment. Nerves often recover if you stop taking the drug causing it or reduce the dosage.

If pain is a symptom of your peripheral neuropathy, speak to a member of your medical team. In some cases, they might refer you to a pain specialist. You could also be given medication, for example:

- an anti-neuropathic pain drug, taken orally (by mouth) such as amitriptyline (Elavil[®]), duloxetine (Cymbalta[®], Yentreve[®]), carbamazepine (Tegretol[®]), pregablin (Lyrica[®]) and gabapentin (Neurontin[®])
- capsaicin cream (a pain relief medicine that is applied directly to the skin) if your pain is confined to one area
- lidocaine (Versatis[®]) plasters (which contain local anaesthetic) if your pain is in only a localised area
- opioids, including tramadol, usually taken orally. These morphine-like drugs may be used if other treatments are not effective.

Different approaches work for different people. You might need to try more than one form of pain relief before you find one that works well for you.

If your neuropathy worsens very quickly, you might be treated with **plasmapheresis** (plasma exchange). Plasmapheresis removes paraproteins from the blood. This is effective in the short-term for some people affected by peripheral neuropathy. It is not used, however, to treat chemotherapy-induced peripheral neuropathy. Macmillan Cancer Support give more information about **plasmapheresis**.

Even with severe neuropathy, for most people, symptoms improve over months or years. In some cases, however, pain, numbness or tingling in your hands and feet can be long-lasting and may never go away completely.

Can I prevent developing peripheral neuropathy?

Talk to your medical team about lowering your risk of peripheral neuropathy. Tell them if:

- **You have any symptoms of peripheral neuropathy.** They can take this into account when planning your treatment. If your lymphoma **relapses** (comes back) and you developed peripheral neuropathy during your first course of treatment, your doctors should consider this. Where possible, they will avoid giving you drugs that could cause or worsen peripheral neuropathy.
- **You might be lacking vitamins from your diet.** Your doctor can check this for you and may prescribe supplements to reduce your risk of developing neuropathy.
- **You drink a lot of alcohol.** To reduce the risk of nerve damage, you might be advised to avoid or lower your alcohol intake while you are having treatment for lymphoma. **The NHS** and the charity **Drinkaware** both give tips on reducing alcohol intake.
- **You are diabetic.** Control your blood sugar levels to reduce the risk of developing peripheral neuropathy.

Researchers are investigating ways of preventing nerve damage. One possibility is to give a neuroprotective treatment with a drug, together with chemotherapy. However, there is currently no conclusive evidence to show whether this is effective.

What can I do to manage peripheral neuropathy?

Peripheral neuropathy can affect your day-to-day life, both practically and emotionally. It's important to find ways to cope with symptoms and to stay safe.

Coping with symptoms

Below are some tips for coping with symptoms of peripheral neuropathy. Speak to your medical team for advice, too.

- Flex and stretch your fingers and toes for a few minutes four times each day.
- Gently massage your fingers and toes.
- Wear gloves and thick socks in cold weather. The cold can worsen symptoms and you may have lowered awareness of temperature, putting you at risk of frostbite.
- Avoid alcohol as it can affect nerve function.
- Ease constipation with a **high-fibre diet** and drinking plenty of fluids. Laxatives may be helpful, but speak to a pharmacist or your doctor before taking them.
- Speak to your GP for help with erectile dysfunction, if it affects you. They can suggest lifestyle changes and may prescribe medication to help.

Some people who have pain as a symptom of peripheral neuropathy find acupuncture helpful. Acupuncture is a type of **complementary therapy** (used in addition to hospital treatment, not instead). The evidence to support the effectiveness of this technique, however, is not conclusive. If you are interested in this approach to managing pain, ask your medical team whether it is suitable for you.

If your neuropathy is severe and you have muscle weakness, pain or balance problems, you might find some day-to-day tasks difficult. Speak to your doctor if this is the case. They may be able to refer you to another **health professional** such as:

- a physiotherapist, who can give you exercises to improve your symptoms. They may also organise daily living aids to make tasks easier, such as walking sticks, splints and supports
- an occupational therapist, who can advise you on adaptations to help you around your home.

The British Pain Society promotes education, training, research and development in all fields of pain. They have a set of **publications for patients**, including a free, downloadable booklet about **understanding and managing long-term pain**.

Staying safe

Nerve damage may mean that you don't receive all the signals you otherwise would, including sensations of touch, pain and temperature. Without these signals, you may not realise you've hurt yourself. It's important, therefore, to take steps to avoid such harm.

Prevent injury:

- Wear gloves for gardening and washing up to prevent cuts and scratches.
- Protect your feet by wearing well-fitting, flat or low-heeled shoes. Seek advice from a pharmacist or your GP if you notice redness or signs of rubbing.
- Keep rooms, stairs and passageways well-lit and clutter-free to avoid tripping over.

Avoid burning or scalding:

- Use oven gloves to prevent burns.
- Check the temperature of baths and showers before you get in. Use a thermometer to do this or have someone else check it for you.

Remember to tell the DVLA if you have peripheral neuropathy.

Emotional impact of peripheral neuropathy

Peripheral neuropathy may not affect you very much or for very long. For some people, however, it can be severe and long-lasting. This can impact **your mood**, for example, you might feel low, anxious and frustrated.

Speak to a member of your medical team. They can suggest practical ways of managing your symptoms and can signpost you to sources of emotional support.

You may also like to connect with other people affected by peripheral neuropathy. You could:

- visit our **online community forum** to find out about other people's experiences and to share your own
- request a **Lymphoma Action buddy** to be put in touch with someone who may be able to relate to you from their own personal experience
- read the **personal stories** of others affected by lymphoma and peripheral neuropathy. **Pat**, diagnosed with **follicular lymphoma**, and **Pam**, diagnosed with **MALT (extra-nodal marginal zone) lymphoma**, both talk about their experiences of peripheral neuropathy.

We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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