

Peripheral neuropathy

Peripheral neuropathy is a type of nerve damage. It can happen as a side effect of some lymphoma treatments. Occasionally, it is caused by the lymphoma itself. This information gives tips to manage peripheral neuropathy and to help stop more nerve damage from happening.

Note that if you drive and you are diagnosed with peripheral neuropathy, you must tell the [Driver and Vehicle Licensing Agency \(DVLA\)](#).

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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.

What is peripheral neuropathy?

The peripheral nerves are like telephone wires; they send electric signals around the body. They go from the brain to, and from, the feet and hands. If the peripheral

nerves are damaged, this communication is disrupted. This is known as peripheral neuropathy.

What are the symptoms of peripheral neuropathy?

The symptoms of peripheral neuropathy depend on which nerves are affected: [sensory](#), [autonomic](#) or [motor](#).

Sensory neuropathy

The most common type of peripheral neuropathy is sensory neuropathy.

Sensory nerves carry messages from the skin and body up to the brain. This includes information about touch, temperature, pain and movement.

Sensory neuropathy can cause reduced sensation (physical feeling), or an increase in unusual sensations.

Sensory neuropathy can happen with [chemotherapy](#) and [checkpoint inhibitors](#) (a type of [antibody treatment](#)). Rarely, it can happen with [radiotherapy](#) in the area of your body treated.

Symptoms of sensory neuropathy can include:

- a prickling or tingling feeling in the part or parts of the body affected – you might feel this as ‘pins and needles’ or numbness
- problems with balance and co-ordination (sensory ataxia), as sensation helps to control movement and balance – this can cause difficulty with tasks like tying laces, doing up buttons or opening jars
- more or less sensitivity than usual to touch and temperature
- feeling pain from something that would not usually cause pain (allodynia)
- a burning or sharp pain, usually in the feet
- a feeling of weakness in your hands and feet
- not being sure where your arms and legs are without looking at them
- feeling that you need to move your legs ([restless leg syndrome](#)).

Sensory neuropathy usually starts in the feet because it affects the longest nerves first. If it gets worse over time, symptoms can spread up your legs and into your hands and arms.

If you have symptoms of peripheral neuropathy, tell a member of your medical team. Sometimes, symptoms can get worse the longer you leave them without treatment.

Autonomic neuropathy

Autonomic neuropathy affects the autonomic nerves. These nerves carry messages to help control body functions that you don't need to think about – for example, your bladder functioning, blood pressure, digestion, heart rate, sexual functioning, and sweating.

Symptoms of autonomic neuropathy can include:

- problems with blood pressure, which can lead to light-headedness or dizziness when you stand up
- tummy problems, such as **constipation**, bloating and feeling sick (nausea)
- not being able to tell when your bladder is full, which can lead to weeing without meaning to (**incontinence**)
- difficulty getting or keeping an erection, known as **erectile dysfunction (impotence)** in males
- your body making too much sweat (**hyperhidrosis**).

Motor neuropathy

Motor neuropathy affects the motor nerves. These nerves are important in movement, as they carry messages from the brain to the muscles.

Motor neuropathy is not a very common side effect of lymphoma treatment.

Symptoms of motor neuropathy can include:

- muscle thinning (wasting) and weakness, which can make tasks like writing, carrying things, standing up from a chair and climbing stairs difficult
- finding it hard to lift the front part of your foot and toes (**foot drop**)
- feeling as though you are not stable on your feet
- muscle twitches, cramps or pains.

You might be referred to a doctor who specialises in disorders of the nervous system (neurologist). To help check for nerve damage, a neurologist might do a **nerve conduction test** and an **electromyography (EMG) test**. Usually, you have these tests done in one appointment.

How can lymphoma and treatment cause peripheral neuropathy?

There are various possible causes of peripheral neuropathy in people with lymphoma. It can happen:

- as a [side effect of lymphoma treatment](#)
- as a [symptom of lymphoma](#)
- because of [another health condition or illness](#).

There is more information about each of these below. We also cover information about some of the risk factors for peripheral neuropathy in our [frequently asked questions](#) section.

Side effect of lymphoma treatment

The most common cause of peripheral neuropathy in people with lymphoma is as a [side effect of treatment](#), particularly with some types of [chemotherapy](#).

If your lymphoma treatment causes or worsens peripheral neuropathy, your medical team might lower the dose or change you to a different treatment.

Chemotherapy-induced peripheral neuropathy (CIPN)

The type of neuropathy CIPN most often causes is [sensory neuropathy](#). Generally, symptoms are mild, such as tingling in your hands and feet.

Symptoms often start after a few courses ([cycles](#)) of chemotherapy – however, it depends on the [type of chemotherapy](#) you have. Occasionally, symptoms get worse or only start once your treatment finishes. You might hear this called ‘coasting’. Usually, the neuropathy then slowly improves over a few months.

Nerve might also be damaged with [radiotherapy](#), [stem cell transplants](#), [targeted therapies](#), and [checkpoint inhibitors](#) (a type of [antibody treatment](#)).

Symptom of lymphoma

Peripheral neuropathy can be a [symptom of lymphoma](#):

- This is quite common in people with [Waldenström's macroglobulinaemia](#) (WM), a rare type of [non-Hodgkin lymphoma](#).

- Rarely, it can happen when lymphoma cells affect nerves – for example, by pushing up against (compressing) them or growing into them (neurolymphomatosis).

Other health conditions or illnesses

Peripheral neuropathy can be a symptom of other conditions and illnesses, such as:

- some autoimmune conditions
- compression of the nerves, typically in the spine
- [diabetes](#)
- [hepatitis](#)
- losing a lot of weight very quickly
- [low vitamin B12 levels](#)
- [obesity](#)
- [shingles](#).

Drinking [a lot of alcohol](#) over a long period of time can also cause nerve damage.

There are also some hereditary (genetic) conditions that can cause peripheral neuropathy, including [Charcot-Marie tooth disease](#) (CMT) and [Hereditary neuropathy with pressure palsies](#) (HNPP).

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 – let them know about any other conditions you have.

How is peripheral neuropathy diagnosed?

If you have symptoms of peripheral neuropathy, you might be referred to a doctor who specialises in disorders of the nervous system (neurologist).

If you are diagnosed with peripheral neuropathy and you drive, you must tell the [Driver and Vehicle Licensing Agency \(DVLA\)](#). You can read more about this in our [frequently asked questions section](#).

Peripheral neuropathy is usually diagnosed through:

- [questions about your symptoms](#)
- [physical examination](#)

- **tests.**

Questions about your symptoms

Your doctor will ask you about your **symptoms** and how they affect your **day-to-day life**. This might include asking you:

- to describe your symptoms, including whether you have **pain**, and which parts of your body are affected
- when you get symptoms and how long they go on for
- whether they started before or after your treatment
- whether you feel sick, faint or more tired than usual
- whether you are having difficulties with bladder control or sexual functioning.

They should also check whether you have any other health conditions and if you are taking any medication for them. This is in case they are having an effect and so that your doctors can make any necessary changes to your treatment plan.

Physical examination

To help diagnose peripheral neuropathy, you are likely to have a physical examination.

Tests for **sensory neuropathy** might include checking:

- your sense of touch – to see if it is higher or lower than is expected
- if you can sense that parts of your body are moving when you can't see them
- the speed of your automatic reactions (reflexes) in response to being tapped on your ankles, knees and elbows
- your balance and coordination, for example, whether you can walk in a straight line.

Tests for **motor neuropathy** might include checking muscle strength in your arms and legs.

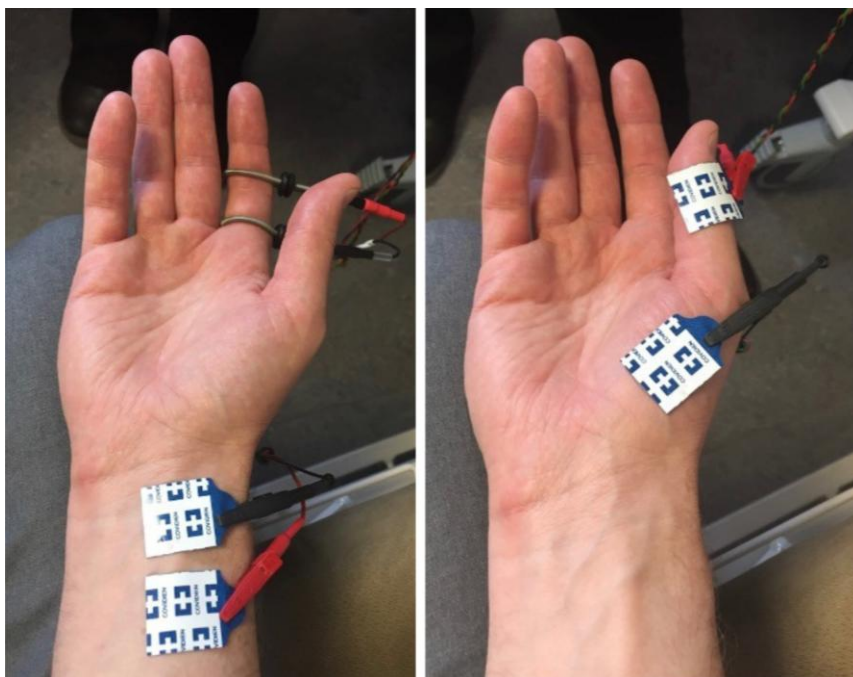
Tests for **autonomic neuropathy** might include checking changes to your blood pressure when you move from lying to standing.

Physical tests

A neurologist carries out tests to check for peripheral neuropathy. These might include:

- A **nerve conduction test (NCT)**, which checks how quickly and how well your nerves carry the signals (impulses). Very slow or weak signals can be a sign of peripheral neuropathy.
- **Electromyography (EMG)**, which measures if your muscles have been affected by motor neuropathy.

Nerve conduction test (left) and electromyography (right)



You might also have [blood tests](#) or [MRI scans](#) to look for other causes of nerve damage.

You can read more about the [tests used in the diagnosis of peripheral neuropathy on the NHS website](#).

Is there any treatment for peripheral neuropathy?

It's important to tell your medical team as soon as possible about any [symptoms of peripheral neuropathy](#). Early action might help to prevent further damage from happening.

If your peripheral neuropathy is caused by your lymphoma treatment, your medical team might make changes to the treatment – for example, by lowering the dose of your chemotherapy, or switching you to different drugs. Although there is no treatment for nerve damage that has already been caused by chemotherapy, it usually improves slowly over a few months.

If the neuropathy is caused as a symptom of lymphoma, treating the lymphoma might improve the neuropathy.

If the neuropathy is caused by other health conditions, it might improve if these are treated. Eating a [healthy diet](#) and [avoiding drinking a lot of alcohol](#) could also help.

Unfortunately, there might be only some, or no improvement in symptoms of peripheral neuropathy.

Your medical team can also offer advice to help you cope with any symptoms you're experiencing. This includes helping to manage [pain](#), if this is a symptom of your neuropathy.

Is there anything to help with pain as a symptom of peripheral neuropathy?

If nerve (neuropathic) pain is a symptom of your peripheral neuropathy, you might be referred to a [pain clinic](#). A specialist can talk to you about ways to help manage the pain. They might also suggest specialist treatments such as [nerve pain \(neuropathic\) drugs](#) and [medicines to put on your skin](#).

[A healthy lifestyle and positive mindset often help people affected by painful peripheral neuropathy. It usually helps to try to keep physically active and mentally active, to eat healthily, to manage any anxiety or low mood, to avoid excess alcohol, to talk to friends and family and to get enough sleep.](#)

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The British Pain Society has resources for [people living with pain](#). These include [publications](#) that are free to download and [patient voices video recordings](#).

You might also be interested in our [useful organisations listing, which has a section on coping with the effects of cancer](#) (including peripheral neuropathy).

Nerve pain (neuropathic pain) drugs

Painkillers such as ibuprofen or paracetamol don't usually help with pain from peripheral neuropathy.

You might be given a nerve pain (neuropathic pain) drug to take as tablets. Examples are [amitriptyline](#), [duloxetine](#), [pregablin](#) and [gabapentin](#). They are sometimes used to treat other conditions, such as depression and epilepsy.

Neuropathic pain drugs usually take a few weeks to work, and you need to take them every day. However, often, they don't work well, or cause side effects. You might therefore need to try a few to find one that suits you.

Medicines to put on your skin

You might be offered medicines to put on your skin (topical treatments), especially if your pain is in only a small part of your skin and is oversensitive to touch or temperature.

Examples include:

- [lidocaine](#), which helps to numb painful areas of your body – you might have this as a cream or as large plasters. This is a form of local anaesthetic.
- other creams that you put on your skin, such as menthol 1%
- capsaicin (taken from red hot chilli peppers) cream or patches.

Other approaches

You might also be interested in trying a [complementary therapy](#), such as [acupuncture](#) or [mindfulness meditation](#). Complementary therapies are sometimes used **as well as** any treatments your medical team recommends, not instead of them.

Some people who have painful [chemotherapy-induced peripheral neuropathy](#) might find [reflexology](#) helpful.

[I found massage & reflexology to be incredibly helpful in improving my blood circulation, reducing muscle tension, and managing pain](#)

and discomfort.

Jana, affected by peripheral neuropathy

If you are interested in trying a complementary therapy, check first with your medical team if it is safe for you, even if it is one you've had before.

If you still have bad pain despite the above treatments, you might be referred to a [pain clinic](#) for more specialist treatments or a pain management programme.

You could also try some of the [tips below to help you cope with peripheral neuropathy](#).

Tips for coping with peripheral neuropathy

Speak to your medical team about any symptoms you experience – they can take any actions as necessary and offer you advice. There are also some [practical difficulties your medical team can help with](#).

Below, we outline tips you could try to help you cope with symptoms of peripheral neuropathy. You might also be interested in the [tips our closed Facebook group shared to help cope with symptoms of peripheral neuropathy](#).

General tips

Some of the general ways you can help yourself are to:

- limit your alcohol intake, as alcohol can affect nerve functioning
- wear gloves and thick socks in cold weather, as cold temperatures can worsen symptoms in your hands and feet
- find ways to help cope with [the emotional impact of peripheral neuropathy](#).

If your sense of touch, pain or temperature are affected

If your sense of touch, pain or temperature are lowered, you might not realise you have hurt yourself. To help avoid hurting yourself:

- wear gloves to protect your skin from cuts and scratches when gardening and washing-up
- protect your feet by wearing shoes that fit well and are flat or low-heeled – avoid walking barefoot

- check your feet every day for blisters – talk to your GP or pharmacist if you notice redness or rubbing
- keep floors free from clutter and well-lit to avoid tripping over or walking into things
- use a thermometer, your elbow, or ask someone else to check the temperature of water in your bath, shower or washing up water
- wear gloves in cold weather as you might not realise that your skin is becoming damaged by the cold.

Practical difficulties your medical team can help with

Speak to your medical team about any difficulties you experience so that they can offer support. A good first point of contact is often your [clinical nurse specialist](#).

If you have pain, muscle weakness or balance problems that make day-to-day tasks difficult, you might be referred to a specialist. For example, a [physiotherapist](#) could suggest exercises to help improve your symptoms. They might also organise for you to have equipment, such as a walking stick. An [occupational therapist](#) can consider changes to make around your home and, if appropriate, your place of work.

Coping with the emotional impact of peripheral neuropathy

Peripheral neuropathy can have a significant effect on your [emotional wellbeing](#). Your mood might be impacted by your symptoms and how they affect your [day-to-day life](#) and [relationships](#).

You could talk to our [Information and Support Team](#) about how your symptoms affect you, physically and emotionally. They might also be able to put you in contact with someone else who has experience of peripheral neuropathy, via our [Buddy Service](#).

Ask your medical team if they can also signpost you to sources of emotional support. You can also search the NHS website to find out about getting support through a [talking therapy](#).

You can read [personal stories](#) of others affected by lymphoma and peripheral neuropathy on our website.

Frequently asked questions about peripheral neuropathy and lymphoma

Below are some frequently asked questions about peripheral neuropathy and lymphoma. Speak to your clinical nurse specialist for guidance specific to your situation.

Can I prevent peripheral neuropathy?

Following a [healthy lifestyle](#) and [eating well](#) might help to reduce the risk of developing peripheral neuropathy. If neuropathy starts, you can reduce the chance of it worsening by telling your medical team. Early action can help to prevent further nerve damage.

Will I get peripheral neuropathy?

Talk to your medical team about your risk of developing peripheral neuropathy with your particular treatment. Nobody can accurately predict who will get neuropathy from lymphoma or its treatment. However, there are a number of individual factors that can affect the risk.

For example:

- **If you have experienced peripheral neuropathy in the past**, your medical team can consider this when they plan your lymphoma treatment. Where possible, they'll avoid giving you treatments that could cause or worsen peripheral neuropathy.
- **If you aren't getting enough of certain vitamins through what you eat**, for example B12, this can increase your risk of developing peripheral neuropathy. Your doctor might make dietary recommendations or suggest dietary supplements.
- **If you drink a lot of alcohol**, 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.
- **If you have diabetes**, your medical team can work with your diabetes team to help control your blood sugar levels. This can help to lower your risk of developing peripheral neuropathy.

Which types of chemotherapy are more likely to cause peripheral neuropathy?

If peripheral neuropathy is likely to be a side effect of your treatment, your doctor should discuss this with you before you start treatment.

The drugs most likely to cause peripheral neuropathy are:

- platinum-based chemotherapy drugs, including cisplatin, oxaliplatin and carboplatin
- vinca alkaloids (a group of [chemotherapy drugs](#)) including vincristine and vinblastine (included in the ABVD chemotherapy regimen)
- [targeted drugs](#) such as [bortezomib](#), [thalidomide](#) and [brentixumab vedotin](#).

However, the likelihood depends on a number of other factors too. Talk to your medical team about your individual situation.

Will my peripheral neuropathy go away?

For most people, [symptoms of peripheral neuropathy](#) improve slowly over time, although they can go on for months or even years. For some people, symptoms last throughout their life.

In general, the more severe the symptoms of peripheral neuropathy, the higher the risk of it going on for some time longer.

With [Waldenström's macroglobulinaemia](#), neuropathy often starts to improve once you begin treatment for the lymphoma.

If peripheral neuropathy gets worse, does this mean my lymphoma is coming back or getting worse?

Worsening peripheral neuropathy or nerve pain can be caused by many different things. For example, heightened [stress](#), medical illness or treatment.

Sometimes, nerve pain temporarily worsens when the peripheral neuropathy is actually getting better.

Depending on the original cause of peripheral neuropathy, worsening symptoms could rarely mean the lymphoma is coming back ([relapsing](#)). If you are worried, speak to your clinical nurse specialist so that they can offer reassurance and, if appropriate, arrange for you to have any [tests or scans](#).

Why should I tell the DVLA if I'm diagnosed with peripheral neuropathy?

If you drive and you are diagnosed with peripheral neuropathy, you must tell the [Driver and Vehicle Licensing Agency \(DVLA\)](#). They then consider whether they think it is safe for you to continue to drive while you are experiencing symptoms. This depends on whether you can safely control the pedals and safely concentrate.

You can find [information on the UK government's website about how to tell the DVLA, what happens after you tell them](#), and about [possible outcomes](#), for example, if you need to have your car or vehicle adapted, or if you need to stop driving for a while. Depending on the nature of your symptoms, this might be reassessed in time.

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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