

Managing Peripheral Neuropathy



Myeloma
Australia

A guide for people with myeloma



Myeloma Australia

Myeloma Australia is a national non profit organisation dedicated to providing information and support for those affected by myeloma. Founded in Victoria in 1998 by three families personally touched by myeloma, the organisation has grown to become a significant provider of services and support for the myeloma community.

Myeloma Australia:

- provides information and support to people living with myeloma, their family, friends and health professionals through its specialist Myeloma Support Nurse led programs
- raises awareness of myeloma
- provides funding for research projects facilitated by our Medical and Scientific Advisory Group
- advocates to state and federal government for support regarding access to new therapies.

To talk to someone about any aspect of myeloma, its treatment and management call the toll-free Myeloma Australia Support Line on 1800 MYELOMA (1800 693 566). The Support Line is available 9am to 5pm (AEST) Monday to Friday. A Myeloma Support Nurse will answer the call in confidence.

Managing Peripheral Neuropathy in Myeloma

This guide is written specifically for people who have been diagnosed with myeloma and who are at risk of, or are experiencing the troubling side effects associated with peripheral neuropathy. It will also be helpful for their families and friends. Peripheral neuropathy is a common side effect of some therapies for myeloma and in some cases a symptom of the disease.



Acknowledgements

Medical Reviewer: Dr Hang Quach, Consultant Clinical and Laboratory Haematologist, St Vincent's Hospital Melbourne and Dr Nicholas Weber, Consultant Clinical Haematologist, Royal Brisbane and Women's Hospital

Editor and Consumer Advocate: Helen Chapman

Consumer Contributor: Judith Stallard.

We would like to thank the reviewers of this guide for their valued contribution to the publication.

ABN 30 476 390 368

Publication date: September 2019



Website: www.myeloma.org.au

Email: support@myeloma.org.au

Myeloma Support Line 1800 MYELOMA (1800 693 566)

Admin: 1300 632 100

Myeloma Australia

PO Box 5017, Burnley, VIC 3121

Printed by Eastern Press Pty Ltd
www.epress.com.au

Contents

4	Introduction
5	What is peripheral neuropathy?
8	What are the symptoms of peripheral neuropathy?
10	How is myeloma associated with peripheral neuropathy
11	Which myeloma treatments cause peripheral neuropathy?
14	Can I prevent or lessen the impact of peripheral neuropathy?
15	Self-monitoring for neuropathy assessment tool
16	Are there other factors that may worsen peripheral neuropathy?
17	Managing peripheral neuropathy
17	Relieving the symptoms of peripheral neuropathy
18	Medications to manage pain
20	Self-management strategies
21	Managing cramps and muscle twitching
23	Strategies to help manage autonomic symptoms
24	Strategies for better circulation
26	Keeping comfortable overnight
26	Relaxation techniques
26	Safety issues to consider
30	Conclusion

Disclaimer

The information in this guide is not meant to replace the professional advice of the doctors and other members of the healthcare team. They are the best people to ask if there are questions about the individual clinical situation.

Introduction

Peripheral neuropathy is a relatively common side effect associated with myeloma and several of its treatments. This guide has been written to increase understanding about peripheral neuropathy. It will firstly explain what peripheral neuropathy is, how the nervous system works, the different ways neuropathy can manifest, what may cause it in those with myeloma, and then finally explain how it may be managed. The information in this guide is not meant to replace the professional advice of the doctors and other members of the healthcare team. They are the best people to ask if there are questions about the individual clinical situation.

Throughout this guide are helpful hints from people living with myeloma. What has worked for one person may not be suitable for another. Ensure to discuss any new management strategy with the treating team.

We strongly advise to read this guide before starting treatment. By recognising the early symptoms of peripheral neuropathy and reporting these to the doctor or nurse, action can be taken which may reduce the severity or progression of the symptoms, and prevent the possibility of irreversible nerve damage.



What is peripheral neuropathy?

‘Peripheral’ means ‘situated away from the centre’ and refers to the outer areas of the body. ‘Neuropathy’ means ‘disease or malfunction of the nerves’.

Neuropathy describes damage to nerves causing impaired function and leading to symptoms that relate to the type of nerves affected. Nerves that can be affected by peripheral neuropathy are the motor (that which controls muscle movements), sensory (that which controls sensations) or autonomic (that which controls automated functions in the body such as blood pressure or bowel movements).

What is the peripheral nervous system?

The nervous system is made up of:

- **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 the arms, hands, fingers, legs, feet, toes, chest, face, and some nerves in the skull. It also includes the nerves that regulate the function of organs we have no conscious control over, called the **autonomic nervous system**. The autonomic nervous system is made up of nerves that connect the spinal cord to the lungs, heart, stomach, intestines, bladder and sex organs.

There are different peripheral nerve pathways:

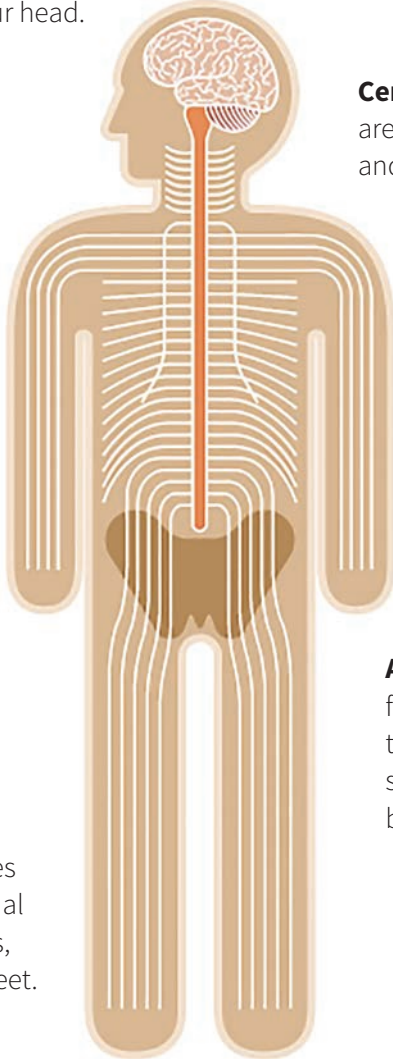
- **Motor** nerve cells carry messages from the brain to the muscles along the motor nerves, to cause movement.
- **Sensory** nerve cells carry messages from sensory receptors all around the body to the brain along sensory nerves. These messages enable us to feel physical sensations such as pain, and touch, and also sense where the body is in relation to the surroundings.

Peripheral neuropathy may damage both motor and sensory peripheral nerves.

.....

Cranial nerves go from your brain to your eyes, mouth, ears and other parts of your head.

.....



.....

Central nerves are in your brain and spinal cord.

.....

.....

Autonomic nerves go from your spinal cord to your lungs, heart, stomach, intestines, bladder and sex organs.

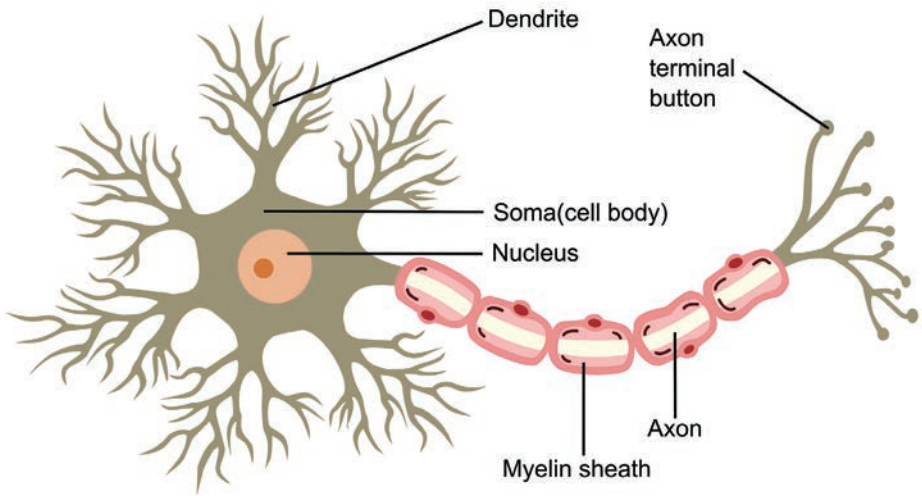
.....

.....

Peripheral nerves go from your spinal cord to your arms, hands, legs and feet.

.....

How do peripheral nerves work?



NERVE CELL

Nerves are the body's communication system. Information about the body's functions, sensation and movement are carried by electrical impulses passed from one nerve cell (neuron) to the next nerve cell along the pathway they form (nerve). When nerves in the peripheral nervous system are damaged, the messages they carry can get mixed up, or perhaps don't get through properly.

What are the symptoms of peripheral neuropathy?

Peripheral neuropathy can cause symptoms ranging from tingling, burning or electric type pains in the hands or feet, through to loss of sensation or numbness, likened to wearing a thin stocking or glove. Peripheral neuropathy caused by myeloma and its treatment usually affects both sensory and motor nerves with similar symptoms on the right and left side (symmetrical). Symptoms usually begin in the toes and fingertips and progress up towards the knees and elbows. Some treatments may also damage the autonomic nerves causing symptoms such as dizziness, digestive problems, early satiety and impotence. Listed below are some of the more common effects that may be experienced when peripheral nerves are damaged.

Some effects of sensory peripheral neuropathy damage are:

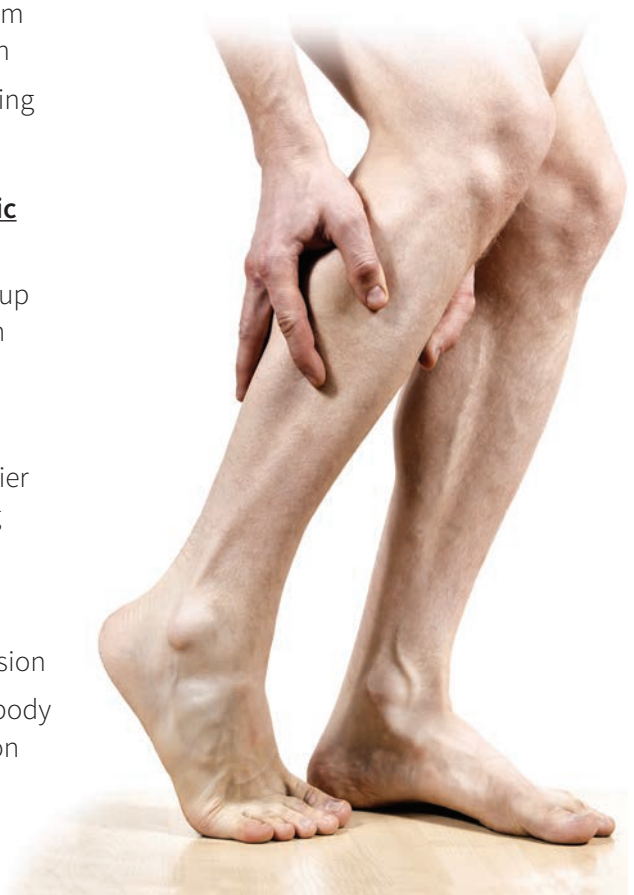
- Tingling, numbness or pain in the hands or feet
- Burning sensation in the hands or feet
- Interference with the sense of vibration
- Reduction in light touch sensation
- Increased sensitivity to touch causing pain (neuropathic pain). This is frequently worse at night
- Altered sensation to stimuli – receiving wrong information, e.g. sensing heat when touching something cold or being unaware of where the feet are on the ground increasing the risk of falls
- Inability to maintain balance when eyes are shut
- The sensation of wearing gloves and stockings
- Loss of reflexes
- Trouble hearing; ringing or buzzing in the ears
- Loss of ability to feel pain or changes in temperature, can lead to failure to sense an injury
- Generalised weakness

Some effects of motor peripheral neuropathy damage are:

- Painful cramps
- Uncontrolled muscle twitching visible under the skin
- Shrinkage of muscle size
- Decreased reflexes
- Inability to do up buttons easily
- Trouble writing
- Difficulty in feeling the shape of small objects
- Difficulty in getting up from a squat or seated position
- Unsteady gait when walking
- Greater risk of falls

Some effects of autonomic nerve damage are:

- Dizziness when standing up from sitting or lying down
- Diarrhoea
- Constipation
- A feeling of being full earlier than normal when eating
- Erectile dysfunction
- Bladder changes
- Changes to the eyes or vision
- Abnormal sweating and body temperature dysregulation



How is myeloma associated with peripheral neuropathy?

There are many causes of peripheral neuropathy. Some are unrelated to myeloma such as: diabetes, alcoholism, vitamin deficiencies, infections (e.g. shingles) and autoimmune disorders. However, myeloma and the treatments used to manage myeloma can cause peripheral neuropathy and it is helpful to understand why it happens to best manage the symptoms and minimise further nerve damage.

It is estimated that up to 13% of people may have symptoms of peripheral neuropathy at the time of being diagnosed with myeloma, with up to 80% of patients developing some degree of peripheral neuropathy as a later complication of myeloma and its treatment.

How does the disease process of myeloma cause peripheral neuropathy?

The disease process of myeloma can cause peripheral neuropathy in a few ways. It is thought that the myeloma protein (paraprotein) produced by the malignant plasma cells, can cause direct damage to the nerve cells, resulting in symptoms of neuropathy. Sometimes, myeloma may be complicated by a condition called amyloidosis (light chain deposition) which can cause peripheral neuropathy. In some people, high levels of paraprotein can lead to thickening of the blood (hyperviscosity) and cause sluggish blood flow, which may also lead to symptoms of peripheral neuropathy. Peripheral nerves, which leave the spinal cord, may also be damaged from a fractured vertebra caused by myeloma bone disease. Other factors causing peripheral neuropathy may include weight loss, metabolic or toxic factors related to the myeloma. Peripheral neuropathy caused by the myeloma disease process should improve with treatment that controls the myeloma.

Which myeloma treatments cause peripheral neuropathy?

Some of the drugs used to treat myeloma may cause peripheral neuropathy therefore careful management is required. It is important to report symptoms of peripheral neuropathy to the treating team if developed while on any of the below mentioned drugs. Managing these symptoms with dose reductions or treatment breaks may prevent permanent nerve damage and ensure the planned cycles of treatment can be completed.

How do current myeloma treatments affect the function of peripheral nerves?

There are two classes or families of drugs that are used to treat myeloma and are known to cause neuropathy. They are: The proteasome inhibitors such as bortezomib (Velcade®) and the immunomodulators such as thalidomide (Thalomid®). These drugs are discussed below in terms of peripheral neuropathy.

Proteasome Inhibiting Drugs

Proteasomes are present in all cells and help regulate cell function and growth. These drugs interfere with the way that proteasomes work, causing myeloma cells to stop growing and die. Myeloma cells appear to be more sensitive to the effects of these drugs than healthy cells.

Bortezomib (Velcade®)

Bortezomib-induced peripheral neuropathy (BiPN) is one of this drug's most common side effects. In the past, bortezomib was routinely administered intravenously (into the vein) however, it can now be also administered sub-cutaneously (into the skin). This change in administration route has seen the incidence of BiPN reduce from 50% to 37% and the incidence of severe BiPN reduce from 15% to 6%. Giving bortezomib sub-cutaneously does not compromise the effectiveness of the treatment.

The exact mechanism of nerve damage is unknown. Although the peripheral neuropathy mostly affects sensory nerves, it sometimes affects autonomic nerves. Usually BiPN is reversible but in some people the symptoms continue after treatment has ended.

What are the symptoms of peripheral neuropathy caused by bortezomib?

People most often describe sensory neuropathy symptoms of pain, numbness, tingling and burning, more commonly in the feet than the hands. About 10% of patients experience an autonomic neuropathy causing a drop in their blood pressure when standing up from the sitting or lying position. This is called postural hypotension. Other symptoms of autonomic neuropathy are diarrhoea or constipation, a feeling of being full earlier than normal when eating, and impotence. If symptoms of bortezomib-induced peripheral neuropathy are going to occur, they usually start during the first few cycles of bortezomib treatment and stabilise around cycle five. It does not appear to increase in later cycles and peripheral neuropathy rarely starts later.

What happens when symptoms occur?

In most patients the symptoms improve or disappear when the dose of bortezomib is reduced or ceased. Therefore, reducing the frequency of doses or reducing the dose itself can help keep symptoms at a low grade during treatment with bortezomib.

See the section on managing peripheral neuropathy (page 17) for practical strategies to help relieve the symptoms.

Next generation proteasome inhibitors

Next generation proteasome inhibitors include carfilzomib (Kyprolis®), MLN9708 (Ixazomib®) and NPI-0052 (Marizomib). While these drugs have the potential to cause peripheral neuropathy, clinical trials have found that the incidence is quite low, in most cases less than 10% and is usually mild in severity.

Immunomodulating Drugs

The exact mechanism of action of the immunomodulatory drugs is still under investigation, however it is thought that they suppress the growth and survival of myeloma cells, inhibit the growth of new blood vessels which myeloma cells need to grow and survive, stimulate the body's immune system to attack myeloma cells and block the activity of chemicals involved in the growth and survival of myeloma cells.

Thalidomide (Thalomid®)

Peripheral neuropathy is one of the more common side effects of treatment with thalidomide. The severity of peripheral neuropathy is related to the dose and length of time on therapy. This is often termed a 'dose limiting toxicity' – which means a toxicity (side effect) that can limit the dose or duration of thalidomide that can be given. The risk of developing peripheral neuropathy with thalidomide increases if some nerve damage already exists at the start of thalidomide treatment.

What are the common symptoms of peripheral neuropathy caused by thalidomide?

Thalidomide-induced peripheral neuropathy can affect both the sensory and motor nerves. Mild peripheral neuropathy, causing tingling in the hands and feet, may occur within 4 months of starting thalidomide treatment. Stinging sensations and numbness in the toes more often than the fingers, are early signs.

Thalidomide can also affect the autonomic nervous system causing symptoms such as constipation and dizziness.

More severe and painful peripheral neuropathy is less common and usually happens after taking thalidomide for longer periods of time (9–12 months or longer). Seventy percent of people taking thalidomide for 12 months or more will develop symptoms. Severe symptoms are less likely to be reversible so it is important that those receiving thalidomide are monitored for early signs of neuropathy during therapy.

What happens when symptoms occur?

As there is no known cure for peripheral neuropathy, its management concentrates on reducing the risk of occurrence and managing the symptoms as they occur. To minimise the risk of peripheral neuropathy, the length and dose of thalidomide therapy should be carefully considered against the potential benefit of the drug. Reducing the dosage, delaying treatment or gradually increasing the dose, are approaches the doctor may use to help control symptoms.

In addition, thalidomide treatment may need to be stopped and alternative treatments offered before peripheral neuropathy becomes severe. This is particularly important because in some cases of severe peripheral neuropathy, the symptoms may continue even after thalidomide has been stopped.

Lenalidomide (Revlimid®) and Pomalidomide (Pomalyst®)

The risk of developing peripheral neuropathy with lenalidomide and pomalidomide is low (2–3%). These drugs are effective myeloma treatments for patients with peripheral neuropathy symptoms and are unlikely to make those symptoms worse.

For more information about myeloma and its treatment contact the Myeloma Support Nurses on the Telephone Support Line (1800 693 566) Monday – Friday 9am – 5pm AEST or obtain a copy of Myeloma a Comprehensive Guide by calling 1300 632 100 or via the website www.myeloma.org.au

Can I prevent or lessen the impact of peripheral neuropathy?

Before starting any treatment that may cause peripheral neuropathy, it is important to be assessed for existing signs of sensory and motor nerve damage. Any changes in nerve function can then be assessed against this baseline. Early peripheral neuropathy symptoms can be treated by dose reduction or delay, so report any symptoms experienced to the treating team.

Because early recognition of peripheral neuropathy is important, it is a good idea to monitor symptoms weekly using an assessment questionnaire such as the one on the following page. Keep a record in a diary or on dated copies of the questionnaire and take to the clinic.

***Box 1.* Vitamin B12 deficiency can increase the risk of developing peripheral neuropathy. Speak to the treating team about ensuring the vitamin B12 level is sufficient before starting a peripheral neuropathy inducing drug.**

Self-Monitoring for Neuropathy

Table 1 *for each question, please tick the box which applies

Name:

Date assessed: / /

I have:

	(1) None	(2) A little bit	(3) Some-what	(4) Quite a bit	(5) Very much
1. Numbness, tingling or pins and needles in my hands and/or feet (S)					
2. Shooting or burning pain in my hands and/or feet (S)					
3. Cramps in my hands and/or feet (M)					
4. Problems standing or walking as it is difficult to feel the ground under my feet (S)					
5. Difficulty walking because my feet drop downwards (M)					
6. Difficulty in feeling the difference between hot and cold water (S)					
7. Difficulty in holding and controlling a pen when I write (M)					
8. Difficulty feeling the shape of small objects in my hands (S)					
9. Difficulty opening a jar because my hands are weak (M)					
10. Difficulty climbing stairs or getting up off a chair because of leg weakness (M)					
11. Difficulty hearing or ringing / buzzing in my ears (S)					
12. Dizziness when I stand up from sitting or lying down (A)					
13. Blurred vision (A)					
14. Difficulty getting or maintaining an erection (men only) (A)					
15. Constipation (A)					

S = sensory A = autonomic M = motor

These questions are a guide for reporting neuropathic symptoms and were adapted from the following validated research tools:

1. Neurotoxicity assessment tool (Tariman et al 2008); FACT/GOG-NTX (Version 4)
2. European Organisation for Research and Treatment of Cancer QLQ-CIPN20 Questionnaire 2013

These questions are about common neuropathic symptoms that occur when using combination myeloma therapies. Completing it in your own time before your clinic appointment will give the doctor or nurse symptom information to record and compare at future appointments. If indicated, a formal assessment, diagnosis and management plan for symptoms may then be completed by the clinician.

Are there other factors that may worsen peripheral neuropathy?

- **Smoking** – interferes with peripheral circulation and nerves so consider stopping. Ask the GP or practice nurse for advice and/or local support. Alternatively ring the Quitline on 137 848.
- **Diabetes** – Monitor blood sugar levels carefully. Chronically elevated blood sugar levels can damage the peripheral circulation and nerves.
- **Alcohol** – Chronic alcohol abuse also frequently leads to nutritional deficiencies (including B12, thiamine, and folate) that contribute to the development of peripheral neuropathy. Speak to the doctor about safely reducing alcohol intake if it is a problem.
- **Infections** – Some bacteria and viruses such as shingles (see box 1) can cause peripheral neuropathy.
- **Other Medications** – Some chemotherapies and other types of drugs not used to treat cancer can also cause peripheral neuropathy.

Box 2. People with myeloma are at increased risk of shingles whether on or off treatment. It can cause long-lasting, intense pain in the area affected. To reduce the risk, antiviral drugs should start within 72 hours of symptoms appearing (increased sensitivity, itching, tingling, or pain before a rash appears). If you suspect shingles contact the GP or treatment centre without delay. Some 'at risk' people receive long term preventative anti-viral drug or keep a current script to be filled if needed. Some people may be prescribed prophylactic antiviral medication as a precaution.

Managing peripheral neuropathy

The management of peripheral neuropathy in myeloma focuses on close assessment of any pre-existing neuropathy; timely dose adjustments of nerve-damaging drugs; ongoing assessment to monitor for worsening neuropathy and strategies to minimise unpleasant symptoms. Changing myeloma treatment schedules or stopping treatment can be difficult to accept, especially if the treatment is working well against the myeloma. Therefore, it is essential to discuss fully with the doctor or nurse what other treatment options are available.

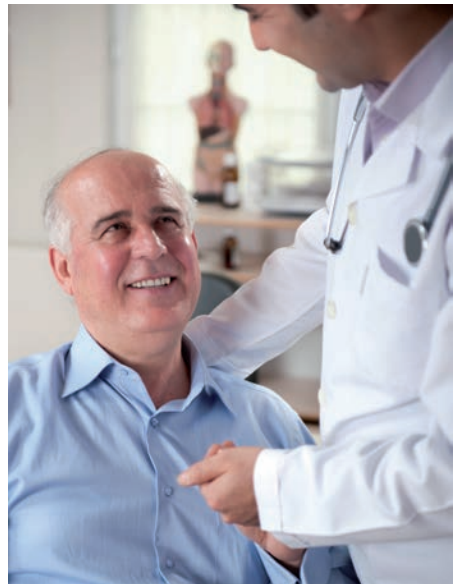
If neuropathy is severe, especially the pain associated with some neuropathy, the doctor may refer to a neurologist, to assess the extent of the nerve damage and give advice on prescription medications and strategies that can ease the pain.

Neuropathy caused by fractures of the spine that have trapped or damaged nerves is treated with painkillers (analgesics), radiotherapy and in some cases spinal surgery to stabilise and increase the height of the vertebrae.

Relieving the symptoms of peripheral neuropathy

There are a variety of remedies that people have reported as being useful in easing the symptoms. Most people learn what helps through trial and error. For some, one option will work whereas others find a combination of methods may be the answer.

Unfortunately, there is little scientific evidence to support one or more effective management strategies. Here we discuss methods the doctor may order, anecdotal methods that have benefited some people, and sensible lifestyle choices.



Medications to manage pain

The pain associated with peripheral neuropathy can vary in intensity and is often described as 'sharp', 'burning', or 'jabbing'. Mild pain can be well controlled with simple pain relievers such as paracetamol. Do not take non-steroidal anti-inflammatory drugs (NSAIDs) such as naproxen, ibuprofen, diclofenac, indomethacin as kidney damage may occur in people with myeloma.

Nerve stabilising drugs (such as pregabalin), low-dose antidepressant drugs that can also work as nerve stabilisers (such as amitriptyline) and antiepileptic drugs (such as gabapentin or carbamazepine) may alter the way the brain perceives the pain and provide some relief.

Opioid drugs such as codeine or morphine may also be helpful to relieve neuropathic pain.

Topical treatments to manage pain

Creams:

- Capsaicin 0.075% (Zostrix HP®) the active ingredient comes from red chilli peppers. It gives a temporary analgesic effect by interfering with how pain messages are sent to the brain, selectively relieving pain without affecting sensory perception from the treated area
- Lignocaine (Xylocaine®) cream or patches produce a temporary local anaesthetic effect which interferes with both pain and sensory receptors
- 1% topical menthol cream. People with long-term chemotherapy-induced peripheral neuropathy have experienced temporary improvement in pain and function using topical menthol

TENS Machine

- Transcutaneous electrical nerve stimulation (TENS) machines can sometimes help reduce pain by delivering tiny electrical impulses to specific nerve pathways at or near the site of pain, through small electrodes placed on the skin. A physiotherapist can provide information on the correct use of a TENS machine.

Acupuncture and Reflexology

- Some people have felt symptomatic relief from peripheral neuropathy by receiving acupuncture or reflexology from a trained practitioner. Consult the doctor first to ensure these treatments are safe for the individual at that time as they may increase the risk of infection, bruising or bleeding.

Supplements that may help repair nerves damage

The below supplements are all available over the counter at chemist shops, supermarkets or health food shops. There is no firm research evidence as yet to support the use of these supplements, so they must always be used with caution and under medical supervision.

We strongly advise discussing any supplement with the doctor before starting, to make sure they are safe and do not interact with other medicines.

- Magnesium and potassium supplements may assist with associated cramping
- Vitamin E
- Amino acids: Acetyl l-carnitine; Alpha-lipoic acid, Glutamine
- Fish and vegetable oils: Omega-3 fatty acids (EPA and DHA); flax seed oil, evening primrose oil
- Vitamin B complex that includes B1 ,B6 , B12 and folic acid

***Box 3.* Please note: While the use of high doses of vitamin C and green tea is not mentioned here, caution is recommended if taking bortezomib (Velcade®). Supplemental vitamin C and green tea may interfere with the action of bortezomib, reducing its anti-myeloma effect.**

.....

“My chemist suggested I try Alpha Lipoic Acid (Lipoec 400). I checked with my haematologist before starting and have been taking two a day for the last six months. It has not given me any relief but it may have stopped the upward movement of the neuropathy in my legs, allowing me to continue with Thalidomide”. Dick, VIC

.....

Self-management strategies

As an overview, maintain good general health to create a good environment for nerves to repair.

- Exercise to improve blood circulation and the oxygen supply to the nerves
- Eat a well-balanced diet using freshly prepared ingredients. Avoid highly processed foods where possible. A balanced diet with ample sources of vitamins B6, B12, vitamin D, folate and healthy fats helps protect the nervous system. Aim to include lots of fresh fruits, vegetables, whole grains and fish rich in omega 3 fatty acids in the diet
- Drink plenty of water and other non-alcoholic drinks
- It is strongly recommended to give up smoking. Smoking constricts the blood vessels that supply nutrients to the peripheral nerves and this can make symptoms worse
- Avoid excessive amounts of sugar and alcohol
- Chronically elevated blood sugar levels also cause damage to peripheral circulation and nerves. Steroid medications such as dexamethasone and prednisolone used in myeloma treatment regimens can elevate blood sugar therefore the blood sugar level should be monitored by the treating team regularly

Reporting new or worsening symptoms is very important to limit more severe neuropathy and permanent damage to nerves. There is a table and chart on page 15 that may be useful as a recording tool. A check for symptoms / progression should be done by the patient and or oncology nurse with each cycle of drug likely to cause neuropathy. Timely dose adjustments or change of therapy may be needed.

-
- *“Foot and leg massage at night as I often had discomfort at the end of the day.*
 - *I was symptom free when swimming. Fortunately I love cold water swimming and swim in the ocean all year round in only bathers and a cap. (Perhaps others would prefer a bath rather than a cold water swim)*
 - *Comfortable shoes.*
 - *Avoid standing for long periods”. Alistair, VIC*
-

Managing cramps and muscle twitching

A cramp is an uncontrollable and painful spasm of a muscle. Twitching is an involuntary contraction then relaxation of a muscle which is sometimes caused by nerve damage. Cramps and twitches often occur at night as muscles try to relax.

Strategies to prevent cramps and muscle twitching

- Drinking tonic water may help with cramps however the sugar content in tonic water should be considered for those with diabetes or at risk of elevated blood sugar while taking steroid medication. Tonic water also contains quinine which can alter the blood's ability to clot. Consult the doctor to make sure it is safe to consume
- The doctor may also check the blood electrolyte (salts) levels and order magnesium or potassium supplements if indicated
- Drink enough fluids to avoid dehydration (avoid alcohol)
- Gentle stretches (see figures pages 22 and 24) or massage
- Gentle exercise to help increase blood flow
- Untuck bed cover corners over the feet, or use a bed frame to relieve pressure and decrease the effort required to move around in bed

Strategies to relieve cramps and muscle twitching

- Stretch the affected area (see figures page 22)
- Massage the cramped muscle

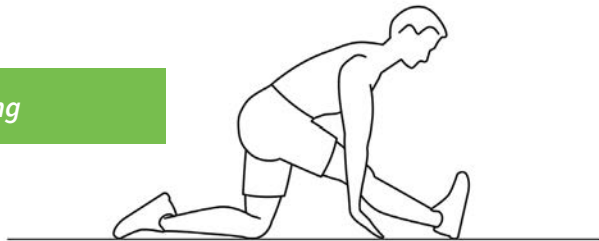
- Undertake some light exercise to improve blood flow to the area
- Take a hot shower or warm bath being careful not to scald the skin

.....

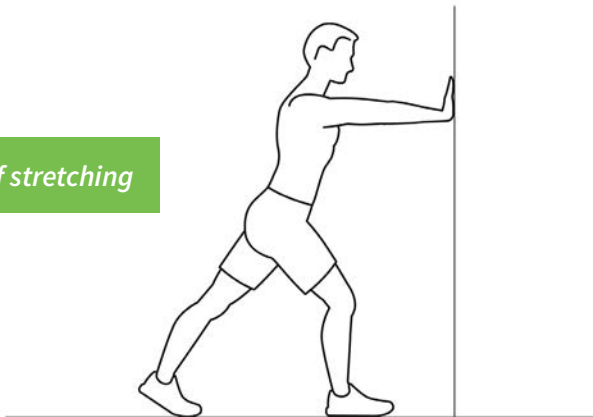
“My neuropathy is a legacy of Thalidomide...I have found that regular walking and stretching the area helps intermittently but if this is not continuous the symptoms return. Also putting feet up at every opportunity. Stated simply it is daily task but the exercise has multiple benefits”. Ken, VIC

.....

Stretching



Hamstring and calf stretching



.....

“The only thing other than pain management is warmth from a heat pack. As peripheral neuropathy can change heat perception be careful not to burn the skin.” Carol, VIC

.....

Strategies to help manage autonomic symptoms

Feeling Dizzy or Light Headed After Standing Up (Postural Hypotension)

- Report any symptoms of dizziness to the doctor
- Regular blood pressure monitoring
- Fluid intake up to 2 - 3 litres of fluid daily (alcohol can make symptoms worse)
- Avoid standing from a lying or sitting position too quickly. Allow time for the blood pressure to adjust
- When getting out of bed, sit upright and gently move the feet and legs to encourage blood flow
- Elevate bed head 5-10 degrees
- 'Pump' your leg muscles when standing for long periods

Constipation and Diarrhoea

- Report any changes in bowel habits from what is normal to the doctor
- Excessive diarrhoea may lead to dehydration; seek advice from the GP or hospital to manage the issue
- If constipation is a problem, increase the dietary fibre and fluid intake and keep a regular exercise regime. In some cases these strategies are not enough and medications are required to help

Sexual Dysfunction

- Some men notice a change in their ability to get or sustain an erection. Report this issue as it can be managed by the doctor: there are medications that may help.
- Some women notice vaginal dryness, lubricants can be helpful or the doctor can recommend other creams
- Both men and women can experience a loss of libido. This may return naturally when treatment finishes. The doctor can also offer management advice

Strategies for better circulation

Massage

Gentle massage with cocoa butter cream (rich in vitamin E) may help relieve pain and discomfort. Massaging twice a day can increase circulation and promote relaxation.

Start massaging at the toes or fingers working gently up the limb. This promotes circulation and enhances lymphatic drainage from the affected area. Some patients find wooden foot massagers helpful for self-massage to increase circulation in their feet. If swelling of the feet is a problem, elevating the feet when resting or sitting down is a good idea. This uses gravity to assist fluid drainage in the legs. Pressure stockings will also help reduce swelling. Reducing the pressure of fluid in the legs may help peripheral neuropathy symptoms.



Exercise

Gentle and regular exercise may help reduce the symptoms of neuropathy. Keeping active helps maintain good blood flow to the hands and feet. The level of intensity should be tailored to individual limits (Exercising beyond limits, could cause muscle fatigue and lactic acid build-up which may worsen peripheral neuropathy symptoms).

A daily gentle walk around the block is a good place to start. Maintaining a regular 20 to 30 minute exercise routine, such as a brisk walk on a treadmill or ride on a stationary exercise bike is ideal. There may also be a local exercise class designed specifically for cancer patients.

The nurse or doctor can help to organise a physiotherapist or exercise physiologist to design a suitable exercise plan. This plan should consider the current level of fitness, pain or bone involvement if present and any other limitations. The Medicare funded Chronic Disease Management Plan provides access to allied health professionals such as physiotherapists and exercise physiologists. Entry to this program is managed through the GP. Some private health insurers also provide a rebate.

Box 4. For further information access our Exercise and Myeloma Fact Sheet or the Exercise chapter in our Living Well with Myeloma book via the website: www.myeloma.org.au or by calling head office 1300 632 100

.....

“My walking gait was affected – I was ‘shuffling’ along rather than striding normally. I thought this was my brain and my body doing the most natural thing. I talked with my Podiatrist who asked me to walk first with my “natural shuffle” and then by concentrating on taking longer steps. He then told me I had to “retrain the brain” by walking each day for 5 minutes while concentrating on taking longer strides. After just a few days I found that even when I wasn’t really concentrating, I was striding out normally. I had ‘retrained the brain!’” Col, NSW

Nurse’s note: Nordic walking classes are great to learn this technique.

.....

Keeping comfortable overnight

Friction of bedsheets overnight can cause irritation to sensitive areas and prevent a good night sleep. Some people wear support stockings to stop the sheets from rubbing on their legs. Silk sheets may also help reduce this friction; alternatively, use a pillow or frame at the end of the bed to lift the sheets from the legs. Ask at your hospital, GP or local pharmacy where a bed frame can be obtained.

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 pain. These therapies also help temporarily distract from discomfort by providing an alternative focal point.



Safety issues to consider

Symptoms of peripheral neuropathy may increase the risk of accidents or injuries because of the lack of sensation, weakness, or clumsiness that may come with damage to the nerves of the skin and muscles.

Table 2 outlines safety measures to should consider.

Please think about the following safety measures:

Table 2.

Safety concern	Preventative measures
Falls	Make sure the lights are on when entering a room
	Remove small rugs and loose floor mats
	Clear walkways of clutter such as toys and footstools
	Wipe spills immediately
	Use skid-free shower and bathroom mats
	Use liquid soap instead of bar soap (to avoid dropping and picking up in bath/shower)
	Avoid slippers and running shoes with thick soles that may increase your chance of tripping
	Wear supportive, well-fitting shoes
	Clear garages and work areas of oil spills
	Store rakes, nails and garden tools out of the walkways
	Use a cane or walking stick if the person is limping or having difficulty walking (or use a walker if arms are weak)
	Skin injuries
Wear warm socks and gloves during cold weather	
Trim nails carefully, avoid leaving nails long or with sharp edges (see hand and foot care below)	
Moisturise skin daily to prevent cracking	
Dry well in between toes to prevent tinea (fungal infection)	
Lower water temperature in the home water heater to avoid burns	
Driving	Ensure the ability to feel brake pedals and steering wheel is not lost. Be alert for changes in reaction time
	Be sure there is sufficient strength and coordination when driving
Fine motor tasks	Use a lighted key ring to unlock doors

.....
“When cooking take care with placement of pot handles as you can spill hot oil on your feet” Anon
.....

“I avoid injuries by being aware of the ground I walk on like rough, scattered rubble. Reducing clutter in the house will reduce the risk of tripping.

Wear boots and gloves when mowing lawns and gardening or cleaning up the shed.

After each such chore, check your feet for any injuries you might not have noticed before. Moisturise feet daily (that will give you the opportunity to check for unnoticed injuries); if bending your legs is difficult, use a mirror” Manny, VIC.
.....

Adaptive aids

If weakness of the hands or feet interferes with daily activities, special equipment may be needed to aid with activity. An occupational therapist can advise on equipment to help overcome the effects of muscle weakness. The Medicare funded Chronic Disease Management Plan provides access to allied health professionals such as occupational therapists. Entry to this program is managed through the GP. Some private health insurers also provide a rebate.

Foot and hand care

It is important to maintain healthy skin when sensory nerves are involved. There may be reduced sensation masking the ability to feel discomfort that would normally alert to a problem if present.

- Inspect hands and/or feet for sores or blisters
- Moisturise feet and hands daily
- Dry in between toes after bathing to avoid fungal infections
- Keep toenails carefully trimmed and filed smooth. Do not leave them long or with sharp edges. If hand weakness makes this difficult, see a podiatrist

The Medicare funded Chronic Disease Management Plan provides access to allied health professionals such as podiatrists. Entry to this program is managed through the GP. Some private health insurers also provide a rebate.



.....
“When buying footwear perhaps half or a full size larger might help and try to go shopping for shoes in the afternoon when your feet are swollen a bit. A visit to the Podiatrist once in a while to measure blood flow to the feet and sensation test might also be helpful”. Manny, VIC
.....

“I have found the best way to walk around is with slip on shoes with memory foam soles. When wearing them you wouldn’t even know you had peripheral neuropathy!” Nicole, NSW
.....

“I find having acrylic nails put on my fingers really helps protect my sensitive fingertips”. Cath, WA
.....

Conclusion

Peripheral neuropathy is recognised as a problem that potentially limits treatment options and severely impacts quality of life. Current research is looking into the mechanisms that cause peripheral neuropathy and how best to control its different presentations and symptoms. People with myeloma are living longer with their disease and so the control of side effects caused by treatments has become even more important. It is now understood that keeping the symptoms of peripheral neuropathy at a low level is the most important strategy in preventing severe symptoms that impact on quality of life and treatment options.



For further information or to discuss any of the information contained in this booklet, call the Myeloma Support Line on **1800 MYELOMA** or **1800 693 566**.

A Myeloma Support Nurse will answer your call in confidence.



Publication date: September 2019

web: www.myeloma.org.au
email: support@myeloma.org.au
myeloma support line: 1800 MYELOMA (1800 693 566)

Admin: 1300 632 100 Myeloma Foundation of Australia Inc.
PO Box 5017, Burnley, VIC 3121