LIVING WITH PN

(Peripheral Neuropathy)

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This information booklet has been prepared by members of

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Whilst this handbook provides helpful information about Peripheral Neuropathy (PN) it is not intended, nor does it constitute, medical or other professional advice.

Diagnosis and advice on medical care or other assessment should be sought from a General Practitioner or a Neurologist or other suitably qualified practitioner.

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What is Peripheral Neuropathy (PN)

PN describes damage to nerves outside the brain and spinal cord (the central nervous system).

Nerves are how the Brain communicates with all parts of the Body. Damage to a nerve will cause messages to/from the Brain to be distorted with varying unwanted results.

The nerves furthest from the central nervous system are often affected first, e.g., the feet and or the hands.

There are three types of nerves within the peripheral nervous system:

- **The Motor System – to get you to move**
- **The Sensory System – to allow you to feel**
- **The Autonomic System – to allow body functions to happen automatically. e.g. Blood pressure regulation, sweating etc.**

Each type will have a characteristic set of symptoms, pattern of development and prognosis. Impaired function and symptoms depend on the type that are damaged.

AXONS (or nerve fibres) are the primary transmission lines of the nervous system and as bundles they form the nerves. Some axons can extend up to one metre or more while others extend as little as one millimetre. The longest axons in the human body are those of the sciatic nerve, which run from the base of the spinal cord to the big toe of each foot. The diameter of axons is also variable mostly miniscule.

There are two types of axons in the nervous system; myelinated and unmyelinated axons. Myelin is made up of lipids (fats) and

proteins which make up an insulating substance. This is formed by two types of glial cells, Schwan cells and oligodendrocytes. In the peripheral nervous system Schwan cells form the myelin sheath of a myelinated axon. In the central nervous system oligodendrocyte cells form the insulating myelin.

With so many different nerves and many different causes, over 100 types of peripheral neuropathy have been identified.

So, we may be similar to others but may not be exactly the same. It follows that what treatment helps one person may be unbearable for another.

Some people may suffer chronic Neuropathic Pain (NeP) whilst some may suffer numbness and feel nothing, and others will experience both.

Either way their condition can seriously affect their day to day living and their overall quality of life.

PN can often be progressive, and the uncertain future course of the illness is cause for great concern for many individuals. In addition, looking "normal" to other people and having to explain their problem adds to their concern.

For many cases of PN no cure has yet been developed and many treatments are "borrowed" from other neurological complaints or purely directed towards pain relief.

It is hoped that this booklet will guide sufferers to find a way to cope with PN and lead to a more productive and enjoyable life.

SYMPTOMS OF PN

Symptoms experienced will depend on the nerve(s) damaged and your own metabolic make up. When first felt they may be dismissed as a minor irritation but can gradually progress to give you concern as to what can be done to fix the problem.

As the feet are the furthest from the central nervous system they are usually first affected – and the hands tend to follow.

In early stages you may notice that your feet become numb, but there may also be paradoxical "extra" sensations. These include burning hot and/or cold sensations, and "pins and needles". These may be accompanied by sharp stabbing pains, and are spasmodic and unpredictable, and people often describe them as "electric shocks".

Gradually walking can become difficult. The impairment in walking can be the result of loss of sensation, neuropathic pain (when walking may be described as "walking on jagged rocks") or weakness. You may also notice that your sense of balance is affected.

When the hands become affected you may have increased difficulty with dextrous tasks such as doing buttons up and handling small items.

An additional complication of loss of sensation in the feet (or hands) is potential for inadvertent injury because of lack of awareness of the trauma. PN sufferers need to exercise care with their feet because they could be seriously damaged without their knowledge. Frequent inspections are vital, and shoes should always be worn.

Excessive sweating or loss of normal sweating may occur at inappropriate times.

Often these symptoms disturb affected individuals more often during the latter part of the day and especially at night and may disturb sleep.

The progress of PN will usually be slow with most people. Treatment can sometimes slow or even stop further progression. In some instances, the condition may even improve on its own accord.

Damage to motor nerves may provide symptoms such as:

- **Muscle weakness**
- **Painful cramps and fasciculations (uncontrolled muscle twitching visible under the skin)**
- **Bone degeneration**
- **Changes in the skin, hair and nails.**

Sensory nerve damage causes a more complex range of symptoms because sensory nerves have a wider, more highly specialised range of functions.

Large sensory fibres enclosed in myelin register vibration, light touch and position sense. Damage to them lessens the ability to feel vibrations and touch, resulting in a general sense of numbness, especially in the hands and feet. People may feel as if they are wearing gloves and stockings, even when they are not. Many people cannot recognise by touch alone the shapes of small objects or distinguish between different shapes.

Damage to sensory fibres may contribute to the loss of reflexes (as can motor nerve damage). Loss of position sense often makes people unable to coordinate complex movements like walking or

fastening buttons or to maintain their balance when their eyes are shut.

Neuropathic pain (NeP) is difficult to control and can seriously affect emotional wellbeing and overall quality of life. NeP is often worse at night, seriously disrupting sleep and adding to the emotional burden of sensory nerve damage.

Smaller sensory fibres without myelin sheath transmit pain and temperature sensations. Damage to these fibres can interfere with the ability to feel pain or changes in temperature. People may fail to sense that they have been injured from a cut or that a wound is becoming infected. Others may not detect pains that warn of impending heart attack or other acute conditions. Loss of pain sensation is a particularly serious problem for people with diabetes, contributing to the high rate of lower limb amputation among those people.

Pain receptors in the skin can also become over sensitised, so that people may feel severe pain (allodynia) from the stimuli that are normally painless (for example, some may experience pain from bed sheets draped lightly over the body).

Symptoms of autonomic nerve damage are diverse and depend upon which organs or glands are affected. Autonomic neuropathy (autonomic nerve dysfunction) can become life threatening and may require emergency medical care in case when breathing becomes impaired or when the heart begins beating irregularly. Common symptoms of autonomic nerve damage can include:

- **An inability to sweat normally (which may lead to heat intolerance)**

- **A loss of bladder control (which may cause infection or incontinence)**
- **An inability to control muscles that expand or contract blood vessels to maintain safe blood pressure levels.**

A loss of control over blood pressure can cause dizziness, light headedness, or even fainting when a person moves suddenly from a seated to a standing position (a condition known as postural or orthostatic hypotension).

Gastrointestinal symptoms frequently accompany autonomic neuropathy. Nerves controlling intestinal muscle contractions often malfunction, leading to diarrhoea, constipation, or incontinence. Many people also have problems eating or swallowing if autonomic nerves are affected.

Remember that we are all different and we may share the same problem, but we will not be "exactly" the same. Although a wide array of symptoms is listed, many people affected only experience a small range of these symptoms.

DIAGNOSIS OF PN

In general, the diagnosis of PN is suspected when individuals present with combinations of the symptoms as previously discussed. The examination by your physician may further heighten the suspicion if there are signs of sensory loss and/or weakness with the loss of reflexes.

The next stage of evaluation is to confirm the diagnosis with nerve conduction/electromyography studies. This is performed by a neurologist. This can help define the severity of the neuropathy and can also define whether the axon (the nerve proper) or the myelin (the covering sheath) is affected. In some cases, this distinction may assist in making a diagnosis of the cause of the neuropathy.

Your physician will usually also perform a battery of laboratory blood tests to try and identify the cause of the PN. This may include tests for diabetes, vitamin deficiencies or toxicities, immune dysfunction or autoimmune diseases and screening for environmental toxin exposures (such as lead or arsenic). If a genetic cause is suspected, DNA testing for some of the more common gene neuropathies may be performed. (These conditions include Charcot-Marie-Tooth disease, hereditary sensory and autonomic neuropathy and amyloid neuropathy).

In some cases, the evaluation may progress to include nerve (and muscle) biopsies. This usually involves taking a portion of a sensory nerve (usually the sural nerve behind the ankle) for laboratory evaluation. If this area is not already numb, there will be permanent loss of sensation of the lateral (or outer part) of the top of the foot.

Unfortunately, even the best medical centres, defining a cause (and therefore potentially a specific treatment) for neuropathies is only possible in about half of cases. The paradox is that the more aggressive and rapidly progressive a PN is, the more likely one is to identify a cause, and the low grade and slowly progressive PN are often termed "idiopathic" (of unknown cause).

TREATMENTS FOR PN

The goal of treatment of PN is to identify the specific cause for the neuropathy and remove or manage the cause. For example, a rare form of autoimmune PN, Chronic Inflammatory Demyelinating Polyneuropathy ("CIDP"), can be managed by immune modifying treatment with intravenous immunoglobulins (antibodies) or plasmapheresis (like kidney dialysis).

Unfortunately, a significant number of people will not have a cause identified, and the other important aspect of treatment therefore is to manage the symptoms and complication of the PN. The management of peripheral neuropathy is often multidisciplinary, involving not only medical staff, but also physiotherapists, occupational therapists, podiatrists and so forth.

Numbness from PN can only be managed by using common sense measures to minimise the impact of the loss of sensation. This may include always wearing protective shoes and checking the numb areas regularly for signs of inadvertent injury.

However other sensory symptoms of PN can frequently be very devastating, and the "positive" (or "extra") sensory symptoms such as pain and distorted sensations ("dysesthesias") may constitute major symptoms in many individuals.

Medications for managing pain, including oral and topical treatments may be useful. Non-steroidal anti-inflammatory drugs (NSAIDs), analgesics (including simple drugs such as paracetamol, but can also include narcotics), antidepressant drugs (which have effect on neuropathic pain independent on their effect on mood), anti-epilepsy drugs (which modify nerve transmission), and anti-arrhythmic drugs (used to control heart irregularities, and act to

modify nerve transmission) are some of the medications your doctor may prescribe. Topical treatments (on the skin in affected areas) can be helpful and include "capsaicin" and other medical combinations which act as local anaesthetic to reduce pain.

Side effects from the medications are common and may be a limiting factor in their use. These therapies may be initiated by your physician or neurologist, but a pain specialist may also help.

Transcutaneous Electrical Nerve Stimulator ("TENs" machine) may be helpful for pain, but the practical use is generally limited to times when the affected individual is sitting or resting.

Some individuals with PN may also develop secondary "restless legs" symptoms, and this may require additional treatment with medications (often with the same medications used to treat other neurological conditions e.g. Parkinson's disease).

Rehabilitation management may also be appropriate in some cases. This may include specific referral to a physiotherapist (usually "neurological physiotherapists"). Specific exercises may be prescribed to try and maintain residual muscle strength and to avoid further "disuse" muscle atrophy and in some cases, deformity (and "contractures"). Orthotics or splints may be recommended to protect, immobilise, correct affected limbs, or to offer functional assistance. Podiatrists are often also involved in the provision of such orthotics. Adaptive equipment and environmental modification may be required in some cases, and usually the assistance of an occupational therapist is requested.

Lastly, but also importantly, psychological complications of a chronic condition should not be overlooked, and treatment for anxiety and depression may be required in some individuals.

CAUSES OF PN

There are many reasons known to cause Peripheral Neuropathy (PN). It is difficult to find which cause can be related to you. An inherited PN can be distinguished from an acquired PN.

INHERITED PN often shows symptoms in infancy or early childhood. The most common inherited PN are a group of disorders referred to as Charcot-Marie-Tooth disease. These neuropathies result from flaws in genes responsible for manufacturing neurons or the myelin sheath. This cause of weakening and wasting of muscles in the lower legs and feet, gait abnormalities, loss of tendon reflexes and numbness in the lower limbs.

ACQUIRED PN usually shows symptoms at an older age (but there are exceptions to the rule) and the possible causes are extensive. For most people it is not possible to determine their exact cause, and they remain classed as "idiopathic".

PHYSICAL INJURY TRAUMA is a common cause of injury to a nerve. Falls, sport activities, work accidents and motor vehicle accidents can all cause nerves to be partially or completely severed, crushed, compressed or stretched.

METABOLIC NEUROPATHIES occur when the chemical process of the living body is affected by things such as:

- **Alcohol use (alcoholic neuropathy)**
- **Low blood sugar (hypoglycaemia)**
- **Kidney failure**
- **Inherited conditions such as porphyria**
- **Severe infection throughout the body (sepsis)**
- **Thyroid disease**
- **Vitamin deficiencies (including vitamins B12, B6, B3, B1 and E)**

DIABETES is the most common cause of PN in the developed world. Most members of the Support Group have not been diagnosed with diabetes but remain susceptible to developing Type 2.

In diabetes the control of blood sugar is faulty, resulting in high blood sugar (but sometimes also low blood sugar). Being overweight makes the development of mature age onset (Type II) diabetes more likely. Diabetes can damage nerves in a variety of ways, including affecting the blood vessels that take nutrition to nerves. Diabetic feet with poor circulation make them particularly vulnerable to ulcers.

RENAL FAILURE is when the kidney cannot perform its normal function of filtering the blood to remove waste products. This can occur when:

- **You have a condition that slows blood flow to your kidneys.**
- **You experience direct damage to your kidneys.**
- **Your kidneys' urine drainage tubes (ureters) become blocked & wastes can't leave your body.**
- **Infection is present.**
- **Medications such as certain chemotherapy drugs, antibiotics etc are used.**

IMMUNE MEDIATED NEUROPATHIES occur where the body's immune system becomes dysregulated. The immune system is a complex system, including a variety of immune cells and immunoglobulins. These are usually defending us against attack from external organisms, such as bacteria, viruses and funguses. When the immune system becomes dysregulated, it can begin to attack the person in error. Other common immune diseases include thyroid disease where antibodies attack the thyroid gland and rheumatoid arthritis where the antibodies attack the joints.

In some cases, the patient may get an infection such as a gut infection. The body produces antibodies to help control the infection but the antibodies "cross react" and can also attack myelin in peripheral nerves.

Whilst there are drugs that can alter the effect of the immune system, care is needed to ensure that the immune system is not suppressed too far to leave the patient too exposed to infection. Also, there are many side effects to be guarded against.

VASCULITIS NEUROPATHIES is where there is an inflammation of blood vessels due to the immune system disorder. This in turn damages the small blood vessels that supply the nutrients to the nerves. If deprived of oxygen and nutrients the axons die causing an axonal neuropathy.

INFECTIOUS NEUROPATHIES can be caused by a wide range of infections. They can be difficult to diagnose and treat.

Some examples include Lyme disease which is caused by a bacterium of the family Borrelia. This germ is passed to humans by being bitten by a tick that usually infects deer. This disease has not previously existed in Australia, but some cases have recently been reported, although there is some doubt whether it was contracted here or overseas.

A more common infection is the Herpes Zoster virus. This causes chicken pox when first encountered. Our immune system suppresses the virus but is unable to remove it entirely from the body, and some virus particles lie dormant and "hide" in the nerve roots. Years later, particularly if you are run down, the body's immune surveillance may be weakened allowing the virus to reactivate, and cause shingles. Affected people may end up with

painful pustules over the area of skin supplied by one of the nerve roots. Even when healed some patients can be left with "post herpetic neuralgia". This is continuing pain due to nerve damage.

Leprosy is a significant cause of peripheral nerve damage. and is the most common cause of PN in the developing world, but rare in Australia. It is caused by a bacterium which has a particular attraction to myelin, which leads to loss of feeling in the limbs.

Human Immunodeficiency Virus (HIV) can be linked to several different forms of a neuropathy.

There are several other lesser-known diseases that can cause PN.

PARANEOPLASTIC NEUROPATHY describes a neuropathy that is associated with a type of cancer. Cancers can produce a reaction in the body's immune system producing antibodies which may be directed at elements in the cancer, but also cross react with neuronal structures. Sometimes cells can produce antibodies without being under the control of the rest of the immune system.

NUTRITIONAL DEFICIENCIES can cause a neuropathy. The lack of vitamins such as thiamine or B12 are especially important. Pyridoxine (B6) is also important, but excess can also cause neuropathy.

TOXIC NEUROPATHIES are caused by poisons taken into the body. The commonest poison causing damage to nerves is alcohol. Whilst moderate alcohol intake may be good for your heart, large amounts, even over short periods, may cause a neuropathy.

People who are exposed to heavy metals (arsenic, lead, mercury, thallium) and other industrial drugs or environmental toxins frequently develop neuropathy.

DRUG INDUCED NEUROPATHIES can be caused by prescribed medicines given for various medical conditions. There is a long list of drugs that are known to cause neuropathy. The commonly known examples are the group of Statin drugs (usually for cholesterol) and several drugs prescribed for treatment of cancer.

Instead of giving you an extensive list of drugs it is better for you to ask your doctor of known side effects, and your pharmacist should be able to provide a detailed pamphlet on each drug you are taking. Sometimes these are already included in the packet.

You are unlikely to experience all side effects shown and not everyone will be affected in the same way. You and your doctor may need to balance the good effects from a drug against the unwanted side effects.

Discovery of new causes continue to be made as does the discovery of new drugs for treatment.

DAILY LIVING

Apart from any treatment your doctor may or may not have prescribed there are several additional options to assist you to cope with your PN. Members have tried a variety of alternatives and if one does not work then the next one may.

YOUR FEET are probably the most neglected part of your body. They don't get a lot of attention until there is a problem. So, we need to change that and give them priority.

It is important to prevent dry skin and cracks developing. A daily application of "Accident Cream" (available from Peripheral Support Group) or a similar moisturiser will keep them soft and supple. But do not apply between the toes. Wearing socks will also help. You should wash and dry your feet daily – remember to dry between your toes. Do not use talcum powder to dry, as it soaks up the moisture, sits there and can encourage athletes' foot.

You need to inspect your feet each day – look for anything unusual or different from yesterday. You should

- **Look at the top and bottom of your feet.**
- **Look in between your toes**
- **Check the back of your heels**

If you have difficulty seeing any part of your feet, then using a mirror would help or get someone else to look.
You need to protect your feet from injury by

- **Not walking bare foot (including in your home)**
- **Use appropriate shoes for the activity**
- **Ensure shoes are comfortable and have an enclosed heel**
- **Avoid exposure to heaters, hot water, hot water bottles etc.**

- **Check shoes before wearing (ensure nothing is left inside)**

PODIATRISTS are the foot specialists. Regular attendance with a Podiatrist (say 4 to 6 weeks) is recommended, especially if you have difficulty seeing or reaching your feet

The podiatrist will be able to carefully cut your nails, remove callouses and professionally inspect your feet. They will be able to detect any problems with your skin, nails, foot function or shape and footwear. Their advice will help manage any problems found and if necessary, make referrals to other professional specialists.

If you have a chronic medical condition, you should ask your GP whether you are eligible to be referred for Enhanced Primary Care (EPC) which would entitle you to receive five services per year funded by Medicare. The services may be spread over more than one type of service (Podiatry, Diabetes, Neurology etc)

SHOES should be bought for comfort not fashion. Correct fitting shoes are vital in the care of your feet. It is advisable to buy shoes in the afternoon when your feet will have swollen to the near maximum. Wear socks like those you will wear with the shoes.

Each foot must be properly fitted as your feet may differ in size and shape. Try the largest foot first. In most cases the larger foot is the opposite from the hand you write with.

Key areas to consider when buying new shoes include

- **Full leather shoes – preferably without seams to minimise rubbing and trauma.**
- **Footwear should not be too short, 10-15mm longer than the foot.**
- **Footwear should be wide enough for widest part of the foot.**

- **The back of the heel should provide firm support.**
- **Fastenings to hold foot stable and secure. NOT "slip-ons" as they tend to be too small to fit or you will subconsciously grip with your toes to keep them on – which leads to problems.**
- **Toe box should not be too pointed or tapered – more rounded and foot shaped.**

It is recommended that you purchase from a specialist footwear shop that could also custom make shoes and orthotic insoles etc.

Referral to an Orthotics Clinic could be part of an Enhanced Primary Care (EPC) if you are eligible, it may enable a reduction in cost of custom-made shoes etc.

Wearing socks inside out can overcome any problems with the seams on socks. You may be able to find seam-free socks.

PAIN is at its most demanding at night and it needs to be countered to enable satisfactory sleep. Medication prescribed by your GP or Specialist may help but often there is a need for something extra. In this regard members have used a variety of creams, gels and sprays and have found different creams to be effective. Again – a case of finding the one that suits you. You might even find a cream that enables you to avoid the need for medication.

Some creams used by members which suited some but not others include:

- **ACCIDENT RELIEF – locally made from the essence of Australian flowers. Available through the Support Group. A smaller 240ml container is available as a cream or a spray.**
  This is sufficient to use as a trial to see if it helps you before outlaying on the larger, more economical one. It

is also convenient to pack for travelling. They can be posted but postage would add to the overall cost. Several members use this regularly and find it helpful.

- **KARMA RUB contains natural liquid magnesium with trace elements Zinc, Iron, Copper and Calcium. It relaxes muscles, nerves and tendons. It may sting but can be mixed with a moisturiser to lessen any discomfort. Again, several members do use this with good results.**

Other products tried by members with differing results are mainly those advertised for relief of arthritis, rheumatism and similar complaints. A discussion with your pharmacist may discover one that could help you, such as;

- **PERSKINDOL - active gel or spray**
- **OZ ARTHRITIS - pain relief cream**
- **OPTI-DERMA - activated healing gel**
- **PAIN AWAY - pain relief therapy**
- **ARTHRO – AID - pain ease**
- **EMLA - with lignocaine and prilocaine**
- **PEDI MED - diabetic foot cream**

All except the Accident Relief are available through Pharmacies.

SHARING PN EXPERIENCES

So much is unknown about PN that it leaves the individual patient feeling lost, alone and not knowing what to do or expect in the future. We thought it may be helpful to include a few "stories" of what has happened to other people with PN.

Faye H tells us:

"I first started noticing symptoms around 2003 on the front of my left ankle. If any clothing touched my leg, I felt light pins and needles/numbness. This went on for a while then the muscle up the side of the shin bone ached all the time. I thought I had shin splints – saw a doctor and was told to take magnesium powder for sore muscles.

The pins and needles patches spread over my lower legs. I started seeing a Neurologist for the headaches I was getting all the time and mentioned the symptoms to him, he was only interested in treating my headaches. After some persistence he did a nerve test on me and ruled out MS and MND and said that my nerve test wasn't 100% but didn't know what it was and to stop worrying about it. I could now dig my fingernails into the muscle next to the shin and have hardly any feeling from it, no pain at all.

In 2009 I went to see another Neurologist and within six weeks (two visits) he had me diagnosed with PN. The symptoms have now spread to my face and arms and my legs annoy me quite a bit and they jump around a lot at night and disturb my sleep. I feel the symptoms are worse in Summer and when I get a little tired or stressed.

On looking back for a cause of PN I mentioned it to my friends and colleagues at work. One other lady I worked with was displaying similar symptoms, though not as bad as mine. Then another said she had been diagnosed with PN – although she is a diabetic. Then a year later another friend from work who is now in Melbourne phoned to say she had been diagnosed with PN – this is four out of nine workers. So, I called the others, and my ex-boss had just started with numbness in toes and the sole of his feet. His sister-in-law who also worked with us had numbness in her hands. Very early days yet – their doctors haven't given them a diagnosis yet.

I believe that my PN was caused by fumes from the photo copier at work. I sat in the room with it going daily, sometimes doing 2000 copies a day. The others were in different rooms in an old caretaker's cottage on school grounds. We used to comment on the fumes all the time, but no action was taken to rectify the situation. After several years the photo copier was moved out the back, but I was the one doing the bulk of the copying in an unventilated room.

I don't know if I will follow through with a claim, may do so if my co-worker's symptoms develop. Sometimes the stress of lawyers etc can do more damage.

The PN Support Group has given me an inner strength and made me realise life goes on, it is great to share with them as sometimes your family don't seem to understand.

I am only taking Vitamin B (multi) and Magnesium each day which seems to be going OK for me. Have been on Endep, slept better but was like a Zombie during the day so I decided to put up with my symptoms for as long as I could and do it naturally."

Murray C tells his story:

I grew up on a farm in New Zealand during the 1950's when it was normal to "go barefoot" both at home and school for most of the year. I've always been impressed by the toughness and adaptability of my feet – the skin would thicken during spring. Until 10 years ago I worked around the house wearing thongs or nothing on my feet.

During 2007 I was working long hours on concrete floors and did not notice that the soles of my shoes were compressed, with no cushioning. I developed "inflamed adventitial bursal" under the head of the 5th Metatarsal i.e. excessive pressure at the ends of the bones caused painful cysts to grow in the fatty layer under the skin. "Diclofenac" cream and a month off work to rest was the cure.

At the same time, I was very slowly losing the sense of touch and gaining pain in the soles of my feet. I mostly ignored the symptoms, and being in my late 50's, presumed it was part of the ageing process. I later mentioned these symptoms to my GP who described them as "peripheral neuropathy" with the comment that it was a common problem, usually with an unknown cause. She added that the condition runs its' own course, is not treatable and testing usually produces no useful results.

I was a regular blood donor at the time and the clinic doctor insisted on a formal diagnosis. This request alerted me to the possibility that peripheral neuropathy was a blanket term, and some causes could be "nasty." A Neurologist performed an electromyograph and other tests. He confirmed the diagnosis and recommended regular exercise to promote blood circulation, avoid injuries and maintain healthy weight.

I am now 64 and over the past six years the symptoms have slowly deteriorated. The reduced sense of touch has extended to the ankles. A contradictory process is also happening – slight pressure on my feet is felt as an irritation, and the nerves monitoring and controlling the position of my feet have affected my balance. The soft tissue of the soles has thinned.

If I spend an extended period on my feet (e.g. over 90 minutes) the soles feel painful and ache the next day. My feet and legs are always cold, so I wear thick woollen socks year-round plus woollen leggings in the winter. When outside I wear custom made sheep skin boots with silicon inserts. At home I have put carpet over the tiled areas. I get about in socks, plus use a mohair blanket to keep warm when sitting and have my feet elevated.

I joined the Peripheral Neuropathy Support Group two years ago. I was relieved to meet other people with similar problems who were keen to swap impressions and remedies.

Supplementary vitamins seemed to help most members, so I started taking magnesium (1 gram per day) and vitamin B12 injections (hydroxocobalamin 1 mg every three months). I found vitamin B12 taken orally is not absorbed effectively. These two vitamins gave me a 50% reduction in symptoms such as tingling and cramps in my feet during the early morning.

Last year there was a brief discussion between two members who described cramps in the calf and thigh muscles causing broken sleep in the early morning. This mirrored a new problem of mine and this led to another specialist assessment, who confirmed the diagnosis of "restless legs syndrome". After very slowly getting the dosage of Pramipexole (brand name Sifrol) up to an effective level I now have minimal trouble with this symptom.

Pramipexole increases dopamine levels and can cause the imagination to take on a life of its own, along with colourful dreams and compulsive activity. Before starting pramipexole, my GP recommended quinine bisulphate (300mg, one tablet at night). This had some benefit, and I still take it in the hope that it allows a lower dosage of pramipexole be effective. I still wake occasionally with mild cramps, stretching exercises while standing gives relief.

My guess on possible causes of my version of peripheral neuropathy would be either herbicide sprays on the farm or the use benzyl benzoate to treat scabies contracted when working in large psychiatric hospitals.

Western medicine is firmly based on scientific logic, as a clear diagnosis from a medical specialist is always an essential starting point. A diagnosis gives confidence to explore the condition and build up on one's knowledge base. It also adds an element of objectivity when dealing with other health professionals. A detailed medical diary, plus retaining copies of all reports is a sound long term strategy.

A diagnosis is only the first step. The real help in dealing with an obscure condition like peripheral neuropathy comes from the support group where information and simple sharing can lighten the load. I also have Meniere's (along with tinnitus and partial deafness) and write with gratitude regarding the value of support groups.

Finally, life is a brief gift, and health is our most precious asset. I hope my story will help others.

Don T tells us of his experiences:

My PN developed slowly over several years. During that time, I always slept with my feet outside the bedclothes.

My GP at the time had no answer and my respected naturopath indicated he knew of no line of treatment. A change of GP could offer no hope. However, a third GP started me off with scripts for Lyrica and Tramadol with a progressive increase to 150g of each at night.

The improvement was immediate at 85%. No longer did I have to rise several times a night to place my feet on cold packs. An increase in the medication resulted in severe side effects of dizziness and nausea. So back to 150g of each.

Members of the support group suggested Vitamin B and for some months I have taken Multi Beach morning. I take the prescribed medication in the afternoon and the Vitamin B each morning.

However, I still discard shoes and socks at every opportunity and walk bare feet in the home.

NB: It is not recommended for people with PN to walk in bare feet and Don is lucky not to have suffered any adverse consequences.

John G tells his story:

In Oct 09 I had three operations on my left foot. The first two failed when the fixing screw had broken because my bones were fragmenting. On the final operation I had the joint fused with

Kryptonite from USA. I also had one toe straightened and toenails removed from two other toes.

I developed burning pains in both feet and it was difficult to wear shoes. I could not stand the weight of bedclothes etc on my feet.

I was diagnosed as having Gout and I was prescribed Progout along with my other medications with no real results. I was referred to a pain specialist then to a Neurologist who gave me an electrical test then advised me I had Peripheral Neuropathy. He put me on Madopar and then I suffered a mild stroke.

I then learnt of the PN Group from my daughter, who had given a talk at a PN meeting. I joined the most helpful group from which I borrowed the book "Numb Toes and Aching Soles" by J.A. Seneff who has PN. I bought a copy of this book and the follow up one "Numb Toes and Other Woes" and I read both. I did some of my own research and tried several alternative medications, lotions etc.

After discussions with my GP, I decided to get the special cream detailed in Senneff's books. This required a doctor's prescription and had to be made up by a Compounding Pharmacy.

The cream was a bit messy, and it stained. I applied it liberally and wore old socks – even to bed. Gradually the pain eased off and eventually disappeared, for which I am most thankful. It may be expensive but, in my case, it was worth the effort and cost.

Whether it was this cream or the combination of other prescribed medications and non-prescription supplements (Caltrate, Fish Oil, Vitamin Mega B and Bio Magnesium) which I still take, I am happy with the results.

As always, check with your medical adviser first to see if it will suit you.

Allan P offers his story:

At 15 years of age, I was employed as a trainee industrial chemist with a multi-national chemical manufacturer in Melbourne, in a very noxious environment. The company made phosphorus and a range of organic and inorganic phosphorus compounds. All employees would have inhaled and been exposed to toxic atmospheres daily.

After working in a laboratory for approximately seven years I moved into sales and marketing areas and escaped the corrosive environment. I was a smoker but have not smoked for some 35 years. I am a moderate drinker.

In 2002 when living in Sydney I had an angioplasty (stent into the heart) and went onto medication to control blood pressure and cholesterol. My medication then was Lipitor 80mg, Ramace 5mg, Plavix 75mg, Minipress 5mg and Minax 50mg. Prior to 2002 I weighed approximately 95 to 100kgs.

In May 2003 I moved to Adelaide and mid 2006 I started to notice an odd feeling on the tops of both feet – no pain just a slight numbness. My GP referred me to a Neurologist who could only find that certain areas of my feet were certainly numb. No treatment was offered (a useless exercise).

We moved to Perth in 2007 and at 71 years of age I was employed as a FIFO worker doing quality control at several sites in the Pilbara. In 2010 I suffered a lower back injury and was no longer required. Prior to this incident I noticed that my balance was deteriorating, particularly in poor light conditions.

My GP referred me to a Neurologist and some months of testing followed which included CAT scans, MRI's, vascular studies, hearing

tests, eye tests and so on. The result of which in 2012 was "you have PN and there is nothing we can do, come back if you get worse"

My current situation is that I suffer with numb feet, shooting pains in my lower limbs but mainly the feet and on recent occasions in the left thigh. My balance is now quite bad, and I walk with a stick. I tend to walk with a high stepping gait.

My GP felt that I was marginally type 2 diabetic but following recent blood tests he is confident that I am not. My weight has dropped to around 78kgs, and I have not taken Lipitor, Plavix or Minipress for around 12months. I endeavour to keep an eye on my health and have regular tests to monitor prostate and bowel conditions.

Fran E's story:

I was married very young, having six children by the age of 26 years to my first husband. Remarried and had another two children to the second husband.

Had a lot of health issues after having such a large family so young. After having a hysterectomy, I had stomach cancer culminating in having a pig's stomach inserted. I was one of the very early recipients of such a procedure.

In 2002 I contracted Non-Hodgkin's Lymphoma and had a very high dosage of chemotherapy. I am currently in remission.

My GP has been treating me since 1997 for my many pains and problems. The crippling night cramps have been horrendous. I have been sent from specialist to specialist to no avail. Most of them

blame the torture my body has experienced over the years as the reason for the condition.

It was eight years ago whilst at my local GP expressing some frustration at the lack of success in my treatment when my GP blurted out "Hell, after all Fran, you have Peripheral Neuropathy" I have the distinct feeling he was sorry he said it. When questioned further he was reluctant to discuss the matter. He admitted that most doctors know little about it and the outlook looked bleak.

Now informed with the name "Peripheral Neuropathy" I investigated further and looked up books etc. I was delighted to find the PN Support Group and its lovely members. They offer advice, information and compassion with empathy.

It was of great comfort to learn I'm not battling this alone.

Peripheral Neuropathy Support Group Inc

The Group was formed in 1998 by June Gascoigne.

Following several years of painful discomfort, she was eventually diagnosed with Peripheral Neuropathy (PN) by a Neurologist. The Neurologist told her that there was no treatment for PN and there was no point in seeing him again.

Initially she was delighted to have a "name" to what was troubling her. However, on thinking about it she realised that she had no idea what the weird name meant. June thought that someone must know something about it, and she placed a three-line advertisement in the "Can You Help" column of The West Australian paper.

There were 35 replies BUT alas they knew nothing more than June and they had thought she had the answers. June kept their names, address and phone numbers and promised to keep in touch if she discovered anything.

Contact was also made by the Western Institute of Self Help (WISH) – now called Connect Groups. They suggested the response warranted development of a self-help group and encouraged June to initiate a meeting. A meeting was held in February 1998 with more than 20 people who were enthusiastic about continuing with monthly meetings.

After about six years the group had grown, and it became evident that it was desirable to form an Incorporated Associated. At this time June recruited her husband to assist with establishing the "Peripheral Neuropathy Support Group Inc". In addition, approval was obtained from the Australian Taxation Office to become a "Tax Concession Charity" (TCC) (so we are not required to pay tax) and a

"Deductible Gift Recipient" (DGR) (so that anyone who donates to the Group would be eligible to claim that amount as a tax deduction.)

Since then, we have become a member of The Neurological Council of WA (NCWA), the peak body covering Neurological disorders.

The PN Support Group continues regular meetings and distributes monthly newsletters. In this way we share ideas, information and experiences with everyone whether they can attend meetings or not. We encourage members to attend meetings with their spouse or other close relative. This encourages people to attend and provides an insight to the nature of the complaint to others in the family.

We now have more than 120 members, with some in every State and many in country areas and most in Metropolitan Perth. Our aim is to increase awareness in the community for both sufferers and medical professionals. As this grows, we would like to develop more research.

Research in Australia is mainly funded through "Diabetes Australia" as diabetics are susceptible to PN. Most of our members do not have diabetes and there is no independent research for these people.

The UK and USA do have greater effort and funding. We try to follow their findings.

We also get useful general medical advice from the Post Polio Group in WA. Tessa Jupp is the main driver in that group. Tessa is an experienced, well qualified and respected Nurse. She has made several guest speaker presentations to our Group and has provided several interesting articles.

Our Group holds a "Circulation Booster" and a "Back Massager" for members to borrow and try out to see if it may help them before they make a purchase. In this way they can avoid paying for a machine that ends up being of no use for them. These machines are not designed for treatment of PN, but they may help some people or help with other additional complaints they may have. Remember they should not be used unless you check with your doctor to make sure your condition or other treatments will not be adversely affected. These were donated by a member (Richard Hardy) who was unable to continue using them because of a heart condition.

We also have a small library of books that are specifically about PN and provide a more detailed coverage of PN. These include

- **Numb Toes and Aching Soles by John A Senneff**
- **Numb Toes and Other Woes by John A Senneff**
- **Nutrients for Neuropathy by John A Senneff**
- **The Care of Neuropathic Limbs by Grace Warren MD**
- **Rewire Your Brain by Dr Stephanie Davies, Dr Nicholas Cooke and Julia Sutton.**
- **Peripheral Neuropathy and NePain "Into the Light" by Gerard Said MD FRCP.**

These books have been kindly donated to the Support Group by members and may be borrowed – usually for one month at a time. You can contact the Support Group by

Mail: Phil Reed at 9 Redfin Cres, BELDON, WA 6027

Phone: 0417 186 337. If no answer, then please text or leave a message with your contact details. We will respond at the first opportunity. If you prefer you can email: phil.r@pnsg.org.au

New members are always warmly welcomed.

Other Useful Contacts

NEUROLOGICAL COUNCIL OF WA (NCWA) employs neurological nurses who may be able to aid/advice regarding your condition. Their service is free and can include:

- **Home visits**
- **Assessment of condition**
- **Education about the disease process**
- **Education about treatment and drugs**
- **Liaison with GPs, Neurologists and other professionals**
- **Development of a care plan**
- **Information about support groups**
- **Referral to health services for support**

Referral may be from a GP or other agency, a partner or a self-referral. These nurses operate in the following regions:

Lotteries House Building, 99-101 Victoria St, BUNBURY WA 6230 telephone:(08) 97924073.

Unit 1, 30 Rose Street, MANJIMUP WA 6258 (08) 97718149.

Lotteries House Building, 211-217 North Rd, ALBANY WA 6330 Telephone: (08) 98415233.

Lotteries House Building, 114 Sanford St, GERALDTON WA 6530 Telephone: (08) 9938 0780.

The Niche, Suite B, 11 Aberdare Rd, NEDLANDS WA 6009.

Telephone: (08) 9346 7533.

Freecall 1800 645 771

NCWA has also established a support group for people seeking social outings/gatherings. It is not specific for your condition as people of all ages with differing neurological conditions are invited to join. They have monthly meetings and prepare a programme of events in advance. The group is called "The Friends of NCWA" and operates from the Niche in Nedlands, with meetings held throughout the Metropolitan area.
For more information telephone (08) 9346 7533.

WA SENIORS CARD is available to permanent residents of WA who are 60 years of age or more and not in full time employment (i.e. 25 hours or less per week averaged over 12 months). The white side can be used to access government concessions and a range of other discounts. The green side is your Transperth Smart Rider card which entitles you to free travel on weekends and public holidays and between 9.00am and 3.30pm on Monday to Friday. Concessional fares apply at other times.

Seniors Information Line (08) 6551 8800 (metro) and 1800 671 233 (country) more info on www.seniorscard.wa.gov.au

TRANSPERTH operate the bus, train and ferry services in Perth. Your Smart Rider card is used to "tag on" and "tag off" for each trip you take. If you do not have a WA Seniors card or are travelling outside the free times, you will need to prepay an amount to cover the planned travel. Transperth info line is 13 62 13 or www.transperth.wa.gov.au

ACROD PARKING PERMITS are available for people with limited mobility. An application form needs to be submitted (including your doctor's medical assessment). A small fee is payable and the permit lasts two years.

Only the permit holder can use the permit, and the permit must be clearly visible on the front dashboard of the vehicle. You may only park in an ACROD bay if YOU need to enter or exit the vehicle.

An ACROD parking permit does not entitle you to free parking, although some local councils may make varying concessions.

e.g., Perth City Council allows first two hours free in a Council parking area (so if you pay for one hour you could stay for three) With street parking you may stay for double the time for which you have paid, provided you are within the maximum time allowed. Check with other councils for their concessions (if any) that apply for where you may want to park.

For ACROD application forms or further information.

Telephone: (08) 9242 5544.

Parking in privately owned car parks is subject to their own rules.

NATIONAL COMPANION CARD SCHEME enables eligible people with lifelong disability to participate at venues and activities without incurring the cost of a second ticket for their companion. Each State independently issues their own card, although they are accepted in all States and Territories. They are accepted by over 4200 businesses and organisations across Australia.

The Companion Card is a card issued to people with a significant and permanent disability who require attendant care support from a companion to participate at most venues and activities. Cardholders present their card when booking or purchasing a ticket from a participating business. Participating businesses will recognise the Companion Card and issue the cardholder with a second ticket for their companion at no charge.

An application form can be downloaded from www.wa.companioncard.org.au or for further information call 1800 617 337.

AGED CARE

There are several services available to help you cope with your PN which may enable you to lead a happy and fulfilling life.

For information on the assessment process and eligibility for different types of Government funded aged care call My Aged Care on 1800 200 422 or go to myagedcare.gov.au

Short-Term and Flexible Care
Short term care services in the home or residential care settings for situations such as restorative care (return to independence), transition from hospital or recovery from an accident or illness.

Entry-Level Support at Home
On-going or short-term care and support services through the Commonwealth Home Support Program (CHSP) including help with housework, personal care, meals and food preparation, transport, shopping, allied help, social support and planned respite (giving your Carer a break).

More Complex Support at Home
Four levels of consumer directed, co-ordinated packages of services through the Home Care Packages Program including personal care, support services and nursing, allied health and clinical services

Residential Aged Care
Personal and nursing care in aged care homes for older people unable to live independently in their own home.

Regional Assessment Service (RAS)
RAS is responsible for assessing CHSP applications. Applications can be mad from the GP or from Hospital discharges.

Aged Care Assessment Team (ACAT)

ACAT have responsibility for both CHSP and Aged Care Packages. Application for assessment or re-assessment can be made by yourself, your carer or GP through My Aged Care telephone:1800 200 422.

The ACAT member will assess and approve your eligibility for home care to help you continue living at home or refer you to other services. They will give you information about home care services in your area, help you access the care you need and help you arrange residential respite care if you need it.

When assessed as eligible for a Home Care Package (HCP) you will:

- **Receive an approval letter from My Aged Care that sets out the level of HCP you are approved to receive and your priority for care.**
- **Be placed in the national priority system for your approved HCP level. Your place will be determined by your priority for care and the time you have waited for a package.**

Waiting time will vary depending on the HCP level approved and the priority of your need. It could take 12 months or more for a package to be available.

You will be advised that you have progressed to near the top of the list and should receive an assigned notice in about a month or so. At this time, you should start to seriously investigate the providers in your area. Then commence to seek interviews to establish what services are offered and the different charges that apply. From the time a HCP is assigned you are given 56 days to sign a contract with a provider of your choice. This will be a hectic time as it takes time to arrange interviews, make comparisons and decide on your choice. If you do not sign a contract in the time allowed you do not lose your approval but will be placed back on the waiting list.

At all these assessments and interviews you should arrange for a relative, friend or carer to join you. It would prove helpful to keep a separate fresh note of who these people are and what organisation they represent. Make notes of important details and be careful to be clear on whether charges quoted are for a daily, fortnightly, monthly or an annual fee. They will all be used, be confusing and it makes comparisons difficult.

NUTRIENTS

In the ideal world we would get all the Nutrients needed for a healthy life from our food. With modern day living, manufactured alternatives and fast-food offerings most of us are missing important nutrients. If left untreated a deficiency can cause severe neurological problems and blood diseases. Vitamins and Minerals that are especially important for our nervous system include:

Vitamin B12

is needed to maintain a functional myelin sheath, together with Vitamin B5 and B9 (folate). Also, if Zinc and Vitamin C are low then B12 can't get into the brain. B12 is stored in the Liver and if the Liver is in poor (fatty) condition then there is less storage available. Take Taurine to improve the liver and available storage.

Some Doctors don't consider B12 that helpful and don't use it when blood levels are not showing a B12 deficiency. Subtle neurological symptoms are evident before B12 deficiency shows up in blood tests. Examination of whether ankle jerk or Achilles reflex are missing or sluggish may indicate B12 is low.

B12 is not absorbed well through the gut and the best way to get results is by B12 injection. It is perfectly safe to have a B12 injection every day as it is water soluble, and any excess is excreted in urine. A trial over 30 days could be worthwhile.

Vitamin B6 (Pyridoxine)

Medical Practitioners tell us that insufficient and excessive amounts of B6 can cause PN. As a rule we cannot ingest excessive amounts from our diet only from supplements. B6 is used to enhance the performance of many supplements although it's not always stated that B6 has been added to the supplement.

B6 can assist with sharp, stabbing, electric shock type pain (i.e. nerve pain). B6 tablets taste sweet or have no taste when needed. The sweeter the taste the more you need. When B6 tablets taste really "YUK" and very bitter that indicates you don't need it. B6 can't work properly if you don't have enough carnitine (in red meat and avocado). B6 can also work for nausea and vomiting. Take all needed dosage in the morning as B6 can keep you awake at night.

Vitamin B1 (Thiamine)

B1 is required for maintenance of membrane potential and proper conductance of nerves and for the generation of nerve impulses. Long standing low B1 causes nerve irritation, diminished reflex response, prickly or deadening sensations, pain and damage to the myelin sheath. A B1 deficiency state is a primary cause of diabetic complications. An elevated blood sugar increases B1 excretion by the kidney 25 times higher than normal. Anyone with low B1 can develop neuropathy with kidney and eye damage and eventual heart failure. You don't have to be diabetic.

Vitamin B7 (Biotin)

B7 is required for carboxylase enzymes that are important in the metabolism of fatty acids and amino acids. B7 deficiency can produce neurological symptoms including depression, lethargy, hallucinations, numbness and tingling of the extremities.

Vitamin C

Vitamin C is an important antioxidant that is required for the synthesis of the neurotransmitter norepinephrine, the reduction of metal (e.g. iron, copper) ions and for the regeneration of Vit E Vitamin C accumulates in the Central nervous System, with neurons of the brain having especially high levels. Vit C deficiency causes

oxidative damage to lipids and proteins in the brain and nerves. Severe deficiency (called scurvy) is potentially fatal. In scurvy, Vitamin C is retained by the brain for neuronal function.

Vitamin E

Severe Vit E deficiency results mainly in neurological symptoms including:

- **Impaired balance and co-ordination (ataxia).**
- **Muscle weakness (myopathy).**
- **Damage to the retina of the eye (pigmented retinopathy).**
- **Restless legs.**
- **Cold sores, upper lip wrinkles and varicose veins.**

Calcium

Calcium ions are important intracellular signals that regulate several physiological processes including neuronal gene expression and neuronal secretion of neurotransmitters. Most people in WA don't need extra calcium.

The extra calcium in Dairy foods can be causing muscle pain. Try a fortnight with NO DAIRY whatever to see if pain levels improve.

Calcium contracts – Magnesium relaxes.

Magnesium

Magnesium is required for more than 300 metabolic reactions, many of which are important for normal brain function.

Magnesium is needed to relax muscles to avoid cramps, sore backs, headaches, migraines, muscle aches and twitches, grinding teeth at night and sensitivity to noise. Take care as magnesium supplements often contain B6.

Iodine

Iodine is needed to maintain and repair the myelin sheath. It is required for the synthesis of thyroid hormones which help your cells activate genes, triggering the production of specific proteins including myelin basic protein (MBP).

Iron

Iron is needed for proper development of oligodendrocytes (the cells that produce myelin) and for several enzymes that synthesise neurotransmitters.

Zinc

Zinc is needed for functioning of the neurotransmitter's norepinephrine, aspartate and GABA.

Before you rush off to try any of the above make sure you attend to your diet first. Then discuss with your doctor whether any of the supplements are suitable for you.
We are all different and the Doctor knows your condition, medications you may already take and the likelihood of reactions from anything new.

INTERNET SITES

We are all aware that there is a mammoth amount of information available on the Internet. However, we need to be cautious because a lot of material is bogus – sometimes in an endeavour to sell a product extravagant claims are made. Other times it may be a deliberate sham.

As a guide we recommend the following sites as being reliable:

- **Commonwealth and State government sites (i.e. those ending in ".gov.au")**
- **Academic and Educational sites (i.e. those ending in ".edu.au")**
- **Information from registered not-for-profit organisations is also usually reliable (i.e. those ending in ".org.au")**

Be more careful with any site ending with (".com" *OR* ."com.au")

To give you a start in your searches it is suggested that the following internet sites may interest you:

- **www.healthinsite.gov.au**
- **www.betterhealth.vic.gov.au**
- **www.nps.org.au to find fact sheets about medications, look for "CMI search" (consumer medicine information)**
- **https://pathologytestsexplained.org.au**
  Laboratory tests translated into accessible language
- **https://www.abc.net.au/news/health**
  From the Australian Broadcasting Corporation. Health news and an email digest.
- **https://www.foundationforpn.org**
  An American (USA) Neuropathy Association.

MEDICATIONS

Members are often confused with different names used for the same drug. To assist in understanding which names contain the same drug, we have listed the pharmaceutical name and then show the different brand names that contain that drug.

Pharmaceutical Name:	Brand name
Amitriptyline	Endep 10mg, 25mg, 50mg
Pregabalin	Lyrica 75mg, 150mg, 300mg
Carbamazepine	Tegretol 100mg and 200mg (also available in sustained release)
	Teril 200mg
Gabapentin	APO Gabapentin 100mg, 300mg, 400mg
	600mg and 800mg
	Gantin 100mg, 300mg, 400mg, 600mg and 800mg
	Neurontin 100mg, 300mg, 400mg, 600mg and 800mg
Duloxetine	Cymbalta 30mg and 60mg
Nortriptyline	Allegron 10mg and 25mg
Imipramine	Tofranil 10mg and 25mg
	Tolerade 10mg and 25mg
Pramipexole Hydrochloride	Sifrol O.25mg (equivalent to pramipexole O.18mg)

PALMITOYLETHANOLAMIDE (PEA) is a natural, protective, fatty molecule produced in our body and in animals and plants. PEA can be found in food such as meat, eggs, soybeans and peanuts. It has been shown to have neuroprotective, anti-inflammatory, anti-nociceptive (anti pain) and anti-convulsive properties. Often in people with chronic disorders, the body does not produce enough PEA, which causes problems.

PEA can be taken with or after food and the capsule can be opened and the contents sprinkled on or mixed with your food. The contents can also be placed under the tongue to dissolve in a few minutes. Dosage commences with one capsule daily for three days and then one capsule twice a day for three days and a gradual increase to four per day suits most people.

PEA may take time to reduce pain and maximum pain reduction may take up to three months. Reduction of pain intensity will be gradual requires some patience and perseverance to achieve good results.

At least one member has successfully reduced his pain, although his numbness is still present. Others have not been successful, and this may be that dosage has been insufficient or not tried for long enough or may not be suitable for the individual. Ask your doctor.

PEA is not currently listed on the Pharmaceutical Benefits Scheme (PBS).

TOPICAL TREATMENTS

Topical lignocaine	**Xylocaine gel**
	Lignocaine gel
Capsaicin	**Zostrix**

	Zostrix HP cream
PAIN RELIEVERS	
Paracetamol	**Panamax**
	Panadol
	Dymadon 500mg
Paracetamol/Codiene	**Panadeine 500/8mg**
	Panadeine Forte 500/30mg
Ibuprofen	**Nurofen 200mg**
	Advil 200mg
	Brufen 400mg
Tramadol	**Tramal**
	APO-Tramadol 50mg quick release and sustained release in 50mg, 100mg, 150mg and 200mg
	Tramedo
	Zydol

Medicinal Cannabis has been approved since 2016 for patients who are seeking to manage conditions such as chronic and neuropathic pain. It is strictly regulated and needs a referral from your GP or specialist and needs approval from Therapeutic Goods Administration (TGA) and the State Medical Authority.

The Tetrahydrocannabinol (THC) compound is not used and

remains banned.

Patients should have exhausted other treatments and not have certain conditions such as pregnancy, heart disease etc.

Could cost between $100.00 to $400.00 per month depending on dosage needed. Not on PBS.

MUSCLE RELAXANTS

Diazepam	**Valium 2mg and 5mg**
	Antenex 2mg and 5mg
Orphenadrine	**Norflex**

The Pharmaceutical name will not change and should be shown on all packaging, often in small print. The brand name has been made up by the Company producing the drug and for marketing purposes will end up being prominently displayed.

MANY THANKS TO THOSE MEMBERS WHO HAVE MADE CONTRIBUTIONS OR SUGGESTIONS FOR THIS BOOKLET AND TO CONNECT GROUPS FOR THEIR HELP IN OBTAINING FUNDING AND ESPECIALLY TO OUR FAVOURITE NEUROLOGIST WHO WAS A GREAT HELP (MUCH APPRECIATED).

This information booklet was compiled by:

Ronald Gascoigne who hopes that it helps

PN sufferers find a better way to enjoy life.