Peripheral Neuropathy!
A Holistic Treatment Guide

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The Treatment Resources Program at the Toronto People With AIDS Foundation provides information and resources to empower people living with HIV/AIDS to be proactive around their health by working in partnership with their health providers. We do not recommend or promote any treatment in particular. We strongly urge those interested in any specific treatment to consult a wide range of resources including a qualified medical and/or complementary therapy practitioner who has experience working with HIV+ patients.

For treatment information and resources,
Contact Rebecca at 416-506-1400 x627 or by e-mail at rgower@pwatoronto.org
Peripheral Neuropathy

What is Peripheral Neuropathy?
The Peripheral Nervous System (PNS) are nerves that connect the Central Nervous System (CNS) to organs and muscles. Peripheral Neuropathy causes damage to these connecting nerves leading to numbness, burning, tingling and even severe pain. This pain is usually located in the toes, feet and legs and sometimes in the hands and arms. Some types of Peripheral Neuropathy involve a breakdown of the nerve endings (axons) that transmit sensations to the brain. It can also damage the coating of nerve fibers (myelin) which affects the transmission of pain signals to the brain.

What Causes PN?
Peripheral Neuropathy can be caused by the progression of HIV infection or as a side-effect of specific anti-HIV medications. For example, Autonomic Neuropathy, which causes damage to nerves that regulate blood pressure, heart rate, digestion, and other body functions, is a direct effect of HIV. There are some specific Nucleoside Reverse Transcriptase Inhibitors (NRTIs or ‘Nukes’) that create Peripheral Neuropathy as a long-term side-effect. The main culprits tend to be the “D-drugs” such as d4T (Zerit/Stavudine), ddI (Videx/Didanosine)and ddC (Hivid/Zidovudine). Other drugs that are used to treat opportunistic infections have also been linked to peripheral neuropathy. These include Flagyl (metronidazole) for amoebic dysentery, Thalidomide (isoniazid) for Tuberculosis, vincristine for Kaposi’s Sarcoma and dapsone for Pneumocystis Carinii Pneumonia (PCP). In addition, peripheral neuropathy is a recognized side-effect of diabetes. There is also some research that has shown that deficiency of vitamins, especially B6 and B12 also contribute to Peripheral Neuropathy.

Am I At Risk?
About 30% of people with HIV develop Peripheral Neuropathy as a result of HIV infection of the nerve cells and/or the development of side-effects from specific medications in Anti-Retroviral Therapy (ART). This means that being HIV-positive is a risk factor for developing Peripheral Neuropathy. Other risk factors include;

- CD4 counts below 100 or a higher viral load
- History of an AIDS defining condition
- History of Peripheral Neuropathy
- High alcohol, cocaine and amphetamines use
- Injection-Drug use combined with NRTIs
- Older than 50 years of age
- Nutritional Deficiencies

Signs & Symptoms
The symptoms of Peripheral Neuropathy can range from being a minor nuisance to a disabling condition. It usually begins with a burning pain and tingling in the feet and fingertips. Symptoms usually start at the soles of the feet and gradually move higher on the body. Some examples of symptoms include;

- Sensation of pins and needles, burning, stiffness in the feet and toes
- Tickling sensations, unexplained pain or sensations more intense than normal
- Difficulty walking or standing
- Extreme sensitivity to touch even to socks, shoes and lying under covers
- Usually affects both sides of the body equally
- Muscle-related symptoms including a lack of muscle control, partial paralysis, muscle atrophy, muscle twitching, difficulty breathing or swallowing, falling and a lack of dexterity.
Managing Neuropathy with Medical Treatment

Medical treatment focuses on symptom relief because there are currently no medications that are able to cure Peripheral Neuropathy. Since certain Anti-Retrovirals (ARVs) produce peripheral neuropathy as a side effect, let your doctor know right away if you have any symptoms because delaying getting off these ARVs can result in permanent problems. Too many people have permanent pain, numbness and burning because symptoms weren’t quickly reported to their doctors or because their doctors hesitated to take them off the ARVs. The following are some treatment options for Peripheral Neuropathy:

If you experience milder forms of Peripheral Neuropathy, paracetamol (500 mg/6 x daily) or ibuprofen 200 mg can be used.

**Anti-Depressants**-
Low doses of tricyclic anti-depressants are used for moderate symptoms of Peripheral Neuropathy because they do not appear to cause mood changes and are especially indicated in neuropathy that causes difficulty in falling asleep. The most common drug of this class is Amitriptyline but other medications including nortriptyline, and despiramine may also be used. It is important to note that these medications do have side-effects and interact with the Protease Inhibitor Ritonavir (Norvir).

**Anti-Seizure/Anti-Epileptic Medications**-
Anti-epileptic drugs, such as Gabapentin (Neurontin), are often the first-line therapy because they are often the most effective against nerve pain. Anti-seizure medications like carbamazepine or mexiletine are sometimes used in cases of more severe symptoms. It is important to note that all medications have side effects. Carbamazepine, in particular, has considerable side effects including dizziness, fatigue, and lack of appetite, dry mouth, nausea, diarrhea, constipation and difficulty focusing the eyes. It also can interact with ART especially with the Protease Inhibitors.

**New Medications**-
No medications have been approved that are able to repair nerve damage. However, several drugs are being studied including lamotrigine (anti-seizure drug), recombinant human nerve growth factor and Tpiramate.

**Improve Your Circulation**
Circulation plays an important role in lessening the symptoms of Peripheral Neuropathy. Even if your symptoms make walking difficult, it is important to do gentle exercise to improve your circulation because movement is important for the muscles, joints and your general health.

- Avoid tight shoes and wear loose fitting socks
- Avoid standing for lengthy periods
- Walk for shorter distances
- Avoid repetitive pressure on the hands
- Raise heels of the mattress with a small pillow to prevent increased pain while sleeping
- Place feet in an ice bath occasionally
- Keep heavy covers off of painful areas
Managing Peripheral Neuropathy with Nutrition

Although there has been no research to date on the effect of nutrition on HIV-related peripheral neuropathy, there has been a lot of research of diabetic neuropathy. Because of the similar processes of these two diseases, there is reason to believe that this research will also apply to HIV-positive people living with neuropathy.

B Vitamins:
B vitamins are really a complex of eight different vitamins including Thiamine (B1), Riboflavin (B2), Niacin (B3), Panthothenic Acid (B5), Pyrodoxine (B6), Biotin (B7) and Cobalamin (B12). Several B vitamins have been shown to help rebuild the myelin sheath around the nerves and repair nerve functioning. Vitamin B12 deficiency is a known cause of neuropathy specific to foot and leg pains. B6 deficiencies are known to cause carpal tunnel syndrome with symptoms of numbness, tingling and pain in the hands and wrists. A study at the University of Athens demonstrated that the long-term use of Biotin (B7) was very effective both for the improvement of nerve conduction and the relief of pain. A suggested dose of B12 is 1000mg/2-7 times per week and 25-50mcg of B6 per day. Injections of B12 may be more effective than the oral dose.

Acetyl-L-Carnitine:
Acetyl-L-Carnitine is a version of L-carnitine which is an amino acid that plays a role in the conversion of triglycerides in the mitochondria and is an essential co-factor in the metabolism of fatty acids. It is believed that this nutrient can protect nerves from oxidization and consequently free radical damage. There have been two studies of HIV-positive people. One study showed that HIV-positive individuals with Peripheral Neuropathy showed a deficiency of L-Carnitine. In another study, 21 HIV-positive individuals who were treated with 1500 mg/twice daily of oral acetyl-l-carnitine for 33 months showed that the symptoms of neuropathy decreased. A suggested dose is 1000mg; 3 times per day.

Alpha Lipoic Acid (ALA):
ALA is an anti-oxidant that helps protect your cells against damage from free radicals. Since it is a small molecule that can move easily between cell membranes, it captures free radicals and can even remove them from other anti-oxidants such as vitamins C and E. Its anti-oxidant properties are thought to protect the nerves from inflammation and the oxidative damage that HIV induces. ALA is also thought to have a protective effect on the liver. There have been a number of controlled clinical trials that have demonstrated its usefulness in reducing both the pain and numbness suffered by those with diabetic neuropathy. A suggested dose is 300-500mg; 2-3 times per day especially in an extended dose format.

Gamma Linolenic Acid (GLA):
GLA is an essential fatty acid that is found in borage oil, grape seed oil, black currant oil and evening primrose oil. It has been shown to be successful in reversing nerve damage in diabetics suffering from peripheral neuropathy. It is thought that GLA may help to rebuild the myelin sheath around the nerves and restore proper nerve conduction. A suggested dose is 240mg; 2 times per day.

Other Vitamins:
Magnesium is one of the nutrients that are often deficient in HIV-positive people and is known to cause Peripheral Neuropathy symptoms. It is necessary for nerve conduction. It can also ease muscle problems, especially muscle cramping.

Know Your Supplements:
Supplements can vary in quality. It is best to consult a knowledgeable provider such as a nutritionist, dietician or a naturopath in the selection of both proper dosage and brand of supplements.
Managing Peripheral Neuropathy with Traditional Chinese Medicine

Traditional Chinese Medicine (TCM) was developed in China over 2000 years ago. TCM consists of acupuncture, herbal therapy and tuina (massage and manipulation involving acupressure). TCM is an energy therapy in which the body's life force (qi) controls the body's mechanisms of homeostasis, immunity and energy flow. Qi is connected through a series of networks called meridians. In this philosophy, health encompasses the whole body as well as the mind and emotions.

It is important that you have a thorough examination by a Western and a Chinese Medical Doctor to determine a diagnosis of Peripheral Neuropathy. In TCM, neuropathy is usually diagnosed as one of five syndromes;

- Dampness in the channels
- Deficient Qi and Xue
- Stagnant Xue
- Cold Stagnation
- Heat or Damp Heat

Self-Care Treatments:

Herbal Hotpacks-
Place one loose cup of fresh rosemary, thyme and mint and wrap in cheesecloth. Secure the ends and soak in boiling-hot water. Remove from water and wrap in a thick towel. Place towel on the floor on top of a garbage bag. Place your bare feet on top of the towel and place another plastic sheet over your feet to seal in the warmth. Remain until towel cools and follow with a foot massage.

Pain-Control Techniques
Meditation, biofeedback, self-hypnosis and deep relaxation can assist with the management of pain. Mindfulness meditation especially can be helpful in coping with pain. Mindfulness is the practice of being present and learning how to quiet the mind.

Exercise
Focus on exercise to increase circulation in the affected areas. Qi Gong is a practice that involves the coordination of different breathing patterns with various physical postures and body movements. It can be very useful in health maintenance including increasing circulation. You can also try low-impact or slow-paced aerobics and stretching exercises.

Self-Massage
Massage areas that are numb or painful using long and smooth strokes. Do not massage areas of the body that are hot to the touch

Acupuncture:
HIV+ people use acupuncture to enhance the immune system, reduce pain and to minimize side effects of HIV medications. Two recent clinical trials examined the use of acupuncture for peripheral neuropathy and showed different results. The second study which was conducted on HIV-positive people with neuropathy showed no difference between acupuncture, placebo and the medication amitriptyline. However, standardized acupuncture points were used and many TCM doctors have pointed out that these points are usually individualized. In spite of these studies, there is a lot of anecdotal evidence that acupuncture does help to alleviate pain associated with peripheral neuropathy.