

Peripheral Neuropathy ^[1]

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What is peripheral neuropathy (PN)?

Many people living with HIV (HIV+) develop problems that involve the nervous system. The nervous system controls thinking, movement, sensations, and feelings.

There are two parts of the nervous system: the brain and spinal cord (central nervous system) and the peripheral nerves (peripheral nervous system). The peripheral nerves run throughout the body like webbing, connecting all the parts of the body to the brain and spinal cord. Any disorder or problem involving damage to the peripheral nerves is called peripheral neuropathy or PN.

Peripheral neuropathy affects over 20 million Americans. The most common form damages not just one nerve (mononeuropathy), but several nerves. This is called polyneuropathy, and is what most people living with HIV are talking about when they say they have neuropathy. Most health care providers know it as a 'sock and glove' nerve problem, because the areas most affected are where you wear your socks and gloves.

What causes PN?

The causes of PN are still unknown. Researchers suspect that either HIV, and/or drugs that are toxic to the nervous system (neurotoxic drugs), or a combination of both may cause damage to the peripheral nerves.

PN happens when the nerves between the feet and/or hands and the spinal cord become damaged. Like frayed wires that can spark or misfire, these damaged nerves do not send their electrical signals properly. As a result, PN can cause feelings of numbness, tingling, burning, itching, or shooting pain. Some people with PN describe their pain as "holding a lit match to my feet," or "walking on broken glass." This chronic (long-lasting) pain can lead those who suffer to become isolated and depressed [2].

Who is at risk of developing PN?

There are certain risk factors for PN:

- Low CD4 cell count [3]
- Older age (greater than 50)
- Medical conditions (for example, diabetes [4])
- Alcohol abuse [5]
- Vitamin B12 deficiency
- Neurotoxic drugs (see below)

Neurotoxic drugs include many that have been used more commonly in the past to treat HIV or HIV-related conditions. The most familiar are the HIV drugs commonly called the "d-drugs."

These d-drugs are rarely used anymore because they are so often toxic to the nervous system:

- ddI (didanosine, Videx)
- d4T (stavudine, Zerit)
- ddC (zalcitibine, Hivid)

Other neurotoxic drugs include:

- Hydroxyurea
- INH (isoniazid)
- Myambutol (ethambutol)
- Flagyl (metronidazole)
- Macrobid or Macrochantin (nitrofurantoin)
- Cipro (ciprofloxacin)
- Dilantin (phenytoin)
- Antabuse (disulfiram, esperal)
- Indomethacin
- Chloroquine
- Certain cancer chemotherapy drugs (e.g., vincristine)

How do you know if you have PN?

Signs of PN include:

- Tingling
- Pins and needles
- Numbness
- Itching
- Feet or hands feeling like they are asleep
- Stumbling when you walk
- Feet or hands throbbing or cramping at night
- Sudden sharp shooting pains

It may be easy for you or your health care provider to overlook slight or occasional sensations like the ones listed above. It is important that you not ignore these symptoms, as they may get worse. If you have any of these symptoms, talk to your health care provider right away so that you can receive early diagnosis and treatment.

Your health care provider will examine you and ask questions about your symptoms, medications and supplements, work environment, exposure to toxins, history of alcohol use, and family history of neurological disease. Usually, PN is diagnosed based on signs and symptoms you report. However, your health care provider may also order tests to determine the type and extent of nerve damage. Blood tests to rule out other potential causes of PN are most common.

If your symptoms are unusual, your provider may refer you to a neurologist, who may suggest nerve conduction velocity testing or an electromyogram (EMG) test for further evaluation. Nerve conduction velocity looks at the speed of the signals your nerves send, and an EMG looks at whether your muscle can respond normally to an electrical signal from a nerve. Other

types of sensory testing and skin biopsies are generally used in research.

PN Treatments

Unfortunately, there are no approved medical treatments to cure PN that is related to HIV. For now, the key to treating PN is to remove the cause and control the pain. If HIV drugs are the cause of the PN pain and those drugs are stopped when symptoms of PN are first noticed, the pain most often goes away. However, this may take up to eight weeks since nerves are slow to heal.

Removing the cause:

You can minimize HIV's effect on your nervous system. It is important to take your HIV drugs on schedule and as prescribed so that your viral load stays low and your CD4 count remains high.

If you are on a d-drug (i.e., Videx, Zerit), talk to your health care provider about stopping or switching the drug. If you decide to stop or switch a drug, it may take six to eight weeks for the PN symptoms to decrease. If the symptoms continue, the PN could be due to HIV.

Relieving the pain:

Controlling the pain can require a combination of drugs and other therapies. Remember to discuss any medications, street drugs, supplements [6], or therapies [7] you are currently using with your health care provider.

- Pain relievers: Using Tylenol (acetaminophen) or Advil (ibuprofen) for mild symptoms of PN may help. If the pain continues, your health care provider may prescribe opioid-based narcotics like codeine. It is important to know that narcotic painkillers can be addicting.
- Anti-seizure drugs: Your health care provider may prescribe drugs such as Neurontin (gabapentin), Lamictal (lamotrigine), Lyrica (pregabalin), or Topamax (topiramate) for nerve pain
- Antidepressants: Some antidepressants have been found to relieve pain by changing the chemicals in your brain that help you feel pain. Drugs such as Elavil (amitriptyline), Pamelor (nortriptyline), or Cymbalta (duloxetine) may help.
- Topical lidocaine patch called Lidoderm
- Transcutaneous Electrical Nerve Stimulation (TENS): A therapy in which gentle electrical current between electrodes placed on the skin eases pain
- Capsaicin: Capsaicin is the chemical produced in chili peppers that gives them their 'heat.' It is available over-the-counter in creams or patches and may cause a burning sensation when you begin using it. It works by reducing a substance that sends pain signals to the brain.
- Complementary therapies [7] such as acupuncture, massage, yoga, hypnosis, biofeedback, and meditation
- Supplements [6] such as alpha-lipoic acid, gamma linolenic acid (found in evening primrose oil), or acetyl-L-carnitine
- A visit to the podiatrist to discuss how to care for your feet and what shoes or socks you should wear

AIMS for PN

The easy way to remember the keys to early diagnosis, treatment and management of PN is to think AIMS:

Awareness ? Take the time to notice what your body feels like and how you move

Information - Never stop asking questions, reading, or trying new drugs, therapies, or tools

Medical Team ? Choose health care providers who are knowledgeable about HIV and neurological problems, and who listen to you and answer your questions

Support ? Finding support is critical. Peer organizations or local HIV support groups [8] can offset the sense of helplessness, isolation, and depression [2] often felt by people who experience chronic pain. Talking with peers can give you an opportunity to share your frustrations and successes with those who understand what you are going through. Come visit The Well Project's blog, A Girl Like Me [9] ? an online community of women living with HIV and the heart of our community ? or get connected [8] to one of our groups.

Tags:

- Peripheral Neuropathy [10]
- nervous system [11]
- central nervous system [12]
- peripheral nervous system [13]
- distal symmetric polyneuropathy [14]
- DSPN [15]
- neurotoxic drugs [16]
- d4T [17]
- Zerit [18]
- ddC [19]
- Hivid [20]
- DDI [21]
- Videx [22]
- tingling [23]
- numbness [24]
- sock and glove disease [25]

Additional Resources

Select the links below for additional material related to peripheral neuropathy.

The Foundation for Peripheral Neuropathy [26]

Peripheral Neuropathy (AIDSmap) [27]

Peripheral Neuropathy (Mayo Clinic) [28]

Types of Peripheral Neuropathy: Inflammatory (Center for Peripheral Neuropathy) [29]

Peripheral Neuropathy (AIDS InfoNet) [30]

Neuropathy and HIV/AIDS (The Body) [31]

[Peripheral Neuropathy \(POZ\)](#) [32]

[Ask the Experts: Peripheral Neuropathy \(CATIE\)](#) [33]

[Peripheral Neuropathy \(American Podiatric Medical Association\)](#) [34]

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Links:

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- [2] <http://www.thewellproject.org/hiv-information/depression-women-and-hiv>
- [3] <http://www.thewellproject.org/hiv-information/understanding-cd4-cells-and-cd4-cell-tests>
- [4] <http://www.thewellproject.org/hiv-information/diabetes>
- [5] <http://www.thewellproject.org/hiv-information/substance-abuse-and-addiction>
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- [22] <http://www.thewellproject.org/tags/videx>
- [23] <http://www.thewellproject.org/tags/tingling>
- [24] <http://www.thewellproject.org/tags/numbness>
- [25] <http://www.thewellproject.org/tags/sock-and-glove-disease>
- [26] <https://www.foundationforpn.org/>
- [27] <http://www.aidsmap.com/Peripheral-neuropathy/page/1730397/>
- [28] <http://www.mayoclinic.org/diseases-conditions/peripheral-neuropathy/home/ovc-20204944>

- [29] http://peripheralneuropathycenter.uchicago.edu/learnaboutpn/typesofpn/inflammatory/hiv_aids.shtml
- [30] http://www.aidsinfonet.org/fact_sheets/view/555
- [31] http://www.thebody.com/index/treat/neuro_neuropathy.html
- [32] <https://www.poz.com/basics/hiv-basics/peripheral-neuropathy>
- [33] <http://www.catie.ca/en/positiveside/summer-2012/ask-experts-peripheral-neuropathy>
- [34] <http://www.apma.org/Learn/FootHealth.cfm?ItemNumber=1864>