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Peripheral Neuropathy

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What Is Peripheral Neuropathy (PN)?

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

Peripheral neuropathy affects an estimated 30 million people in the US.

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 parts of the body to the brain and spinal cord. Any disorder or problem that involves damage to the peripheral nerves is called peripheral neuropathy or PN.

Peripheral neuropathy affects an estimated 30 million people in the US. 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 healthcare providers know it as a 'sock and glove' nerve problem because the areas most affected are the feet and hands.

What Causes PN?

There are many causes of neuropathy, most commonly diabetes; however, the causes of PN due to HIV are not completely understood and may involve multiple factors. Researchers suspect that either HIV itself, 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, less commonly, 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 a 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 from it to become isolated and [depressed](#).

Who Is at Risk of Developing PN?

There are certain risk factors for PN:

- Low [CD4 cell count](#)
- Longer duration of HIV infection
- High [viral load](#) or not being on HIV treatment
- Older age (greater than 50 years)
- Medical conditions (for example, [diabetes](#))
- [Alcohol abuse](#)
- Vitamin B12 deficiency
- Neurotoxic drugs (see below)

Many drugs that were used more commonly in the past to treat HIV or HIV-related conditions are neurotoxic. The most familiar are the HIV drugs commonly called the "d-drugs." These drugs are rarely used anymore because they are so often toxic to the nervous system:

- ddl (didanosine, Videx)
- d4T (stavudine, Zerit)
- ddC (zalcitabine, Hivid)

Other (non-HIV) neurotoxic drugs include:

- Zyvox (Linezolid)
- Hydroxyurea
- INH (isoniazid)
- Myambutol (ethambutol)
- Flagyl (metronidazole)
- Macrobid or Macrodantin (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 healthcare provider to overlook slight or occasional sensations like the ones listed above. It is important that you not ignore these symptoms, because they may get worse. If you have any of these symptoms, talk to your healthcare provider right away so that you can be diagnosed and treated early.

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Your healthcare provider will examine you and ask questions about your symptoms, medications and supplements, work environment, exposure to toxic substances, history of alcohol use, and family history of neurological disease. Usually, PN is diagnosed based on signs and symptoms you report as well as your physical exam. However, your healthcare 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 very common.

If your symptoms are unusual, your provider may refer you to a neurologist, who may suggest nerve conduction velocity testing or an electromyography (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 muscles can respond normally to an electrical signal from a nerve. Other types of sensory testing and skin biopsies are generally used only 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. This may take up to eight weeks because nerves are slow to heal. *Do not stop any drugs without first talking to your healthcare provider.*

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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 healthcare 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 itself.

Relieving the pain:

Controlling the pain can require a combination of drugs and other therapies. Remember to discuss any medications, street drugs, [supplements](#), or [complementary therapies](#) you are currently using with your healthcare provider.

- Pain relievers: Using Tylenol (acetaminophen) or Advil (ibuprofen) for mild symptoms of PN may help
- Anti-seizure drugs: Your healthcare 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.
- Transcutaneous Electrical Nerve Stimulation (TENS): A therapy in which a 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.
- Lidocaine cream or patches
- [Complementary therapies](#) such as acupuncture, massage, yoga, hypnosis, biofeedback, and meditation
- Cannabis: Smoking [cannabis](#) ('weed') may relieve the pain but smoking itself has negative effects on your body
- [Supplements](#) such as alpha-lipoic acid
- A visit to the neurologist to figure out the extent of the PN damage, and which treatments are recommended
- A visit to the podiatrist to discuss how to care for your feet and what shoes or socks you should wear

Narcotic drugs ([opioids](#) are one kind of narcotic) had been used in the past to relieve the pain of PN, before the discovery of other effective methods like the ones outlined above. Narcotics are not a first step in treatment for PN.

AIMS for PN

The easiest 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 – If possible, choose healthcare providers who are knowledgeable about HIV and neurological problems, and who listen to you and answer your questions

Support – Finding support can be helpful. Peer organizations or local HIV support groups can offset the sense of helplessness, isolation, and [depression](#) 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. If you would like to connect with others, visit Well Project's blog, [A Girl Like Me](#) – an online community of women living with HIV – or [get connected](#) to one of our groups.

Additional Resources

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

- [The Foundation for Peripheral Neuropathy](#)
- [Peripheral Neuropathy \(POZ\)](#)
- [Peripheral Neuropathy and HIV \(aidsmap\)](#)
- [Peripheral Neuropathy \(Mayo Clinic\)](#)
- [What Is Peripheral Neuropathy? \(American Podiatric Medical Association\)](#)
- [Peripheral Neuropathy \(Cleveland Clinic\)](#)
- [Peripheral Neuropathy \(US National Institute of Neurological Disorders and Stro...](#)
- [Peripheral Neuropathy \(Johns Hopkins Medicine\)](#)
- [Peripheral Neuropathy \(American Diabetes Association\)](#)
- [Peripheral Neuropathy \(International Association of Providers of AIDS Care\)](#)



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