

# PERIPHERAL NEUROPATHY



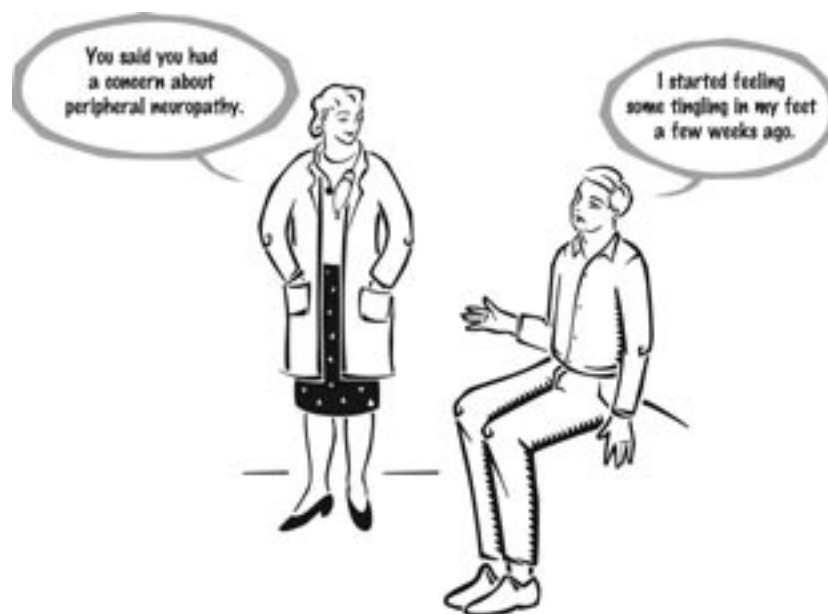
information on how to prevent, diagnose and treat this common nerve disease

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Some people living with HIV will develop a disease of the nerves called *peripheral neuropathy*, or PN. It's a common condition that affects nearly 20 million people in the US, more often in older adults. About 1 in 3 people with diabetes face PN, and it affects about 1 in 3 people with HIV at some time in their lives. PN can profoundly affect a person's quality of life as well as her or his family or caretakers.

*Peripheral* means *beyond the main part* while *neuro* means *nerves* and *pathy* means *disease*. Since your brain and spinal cord are the center for your nervous system, PN is found in other parts of your body.

Normally, PN affects the toes, feet and legs first. The fingers, hands and arms can become affected as well.

When diagnosed and treated early, PN can often be controlled. For some, though, managing PN can be challenging. It may take some time for you and your doctor to treat your PN properly. Certain treatments may work in some people but won't work in others. Even after treatment, PN symptoms may still persist though probably to a lesser degree. This publication provides an overview of PN, including ways to manage and treat it.

## What is peripheral neuropathy?

The brain and spinal cord make up your *central* nervous system (CNS). This system is connected to your *peripheral* nervous system (PNS), which are the nerves found throughout the rest of your body. These nerves serve your limbs and organs. These systems communicate to each other through nerve cells.

Unlike the brain and spine which are covered by bone, peripheral nerves are not covered, leaving them exposed to possible injury and infection. In general, PN is caused by damage to your body's peripheral nerves—to its cell body, its nerve fiber or its coating. This damage impairs your body's ability to communicate with your skin, muscles and internal organs.

## What causes it?

There are over 100 types of PN and many different causes for it. They include injury, inherited diseases, chronic conditions, infections, medicines, lack of vitamins or HIV itself. A common example of PN is *carpal tunnel syndrome*.

Peripheral neuropathy can be due to damage to the coating (*myelin*) of the nerve endings. The damage may also be due to a breakdown of the nerve endings themselves. Some chronic conditions can also cause PN, like diabetes, arthritis and lupus, as well as some viral infections, like CMV or herpes. In the US, PN is caused most often by diabetes and alcoholism.

For those living with HIV, HIV itself can cause PN by infecting nerve cells. Some HIV drugs—notably Zerit (stavudine, d4T) and Videx (didanosine, ddI)—and drugs used to treat HIV related infections, like Dapsone (diaminodiphenyl sulphone), can also contribute to nerve damage. More recently approved HIV drugs have not shown this risk for PN, though it may take several years before evidence of this side effect appears.

## Who is at risk?

Several risk factors put people living with HIV at a higher risk for PN. These include a history of PN, higher viral load, CD4 count below 100, an AIDS-defining condition, use of drugs that damage nerves, diabetes, poor nutrition, and heavy use of alcohol. Peripheral neuropathy more often appears in later stage HIV disease.

Men and women seem to have PN at about the same rate. Older adults are more at risk for PN. People who do not get enough vitamins (especially B12 and E) and minerals in their diets or through supplements are also at higher risk. People are more at risk when they get too much vitamin B6 or drink excessive amounts of alcohol.

Several drugs commonly used in HIV disease can increase the risk of PN: Zerit, Videx, Dapsone, INH (isoniazid), Flagyl (metronidazole), Oncovin (vincristine), Myambutol (ethambutol) and Zyvox (linezolid). If you take any of these, or especially two or more of them, you may be more at risk. The risk increases yet again if you also have any of those conditions listed above.

## What are the symptoms?

Symptoms can range from mild to severe and perhaps disabling. Sometimes PN is present even without symptoms. When people first get PN, they normally feel sensations like tingling, weakness, numbness, pinching, buzzing or stiffness in their toes and feet or fingers and hands. When PN is mild, you may feel annoyed with the sensation.

As it gets worse, people report having a cramping, burning, throbbing or shooting pain. When it's more severe, you may have trouble standing or walking. Some people refer to the pain as "frostbite", "pins and needles sticking in", "a lit match held to my foot" or "walking on broken glass". This could be so severe that wearing clothes or sleeping under blankets is painful. Less common symptoms include dizziness, diarrhea and impotence.

Symptoms of PN vary from person to person. They can appear suddenly, come and go, or persist over time. They usually affect both sides of the body at the same time, and they may get worse at night. You may also notice different sensations when you pick up or move something with your hands or feet.



## How is it diagnosed?

People living with HIV can have conditions of the nervous system other than PN, so it's important to describe your symptoms correctly to ensure an accurate diagnosis. Talking to your health provider sooner rather than later will also improve your diagnosis and outcome, and reduce further damage to your nerves.

Your doctor will base her or his diagnosis of PN by talking to you about your symptoms. No actual tests are needed for the diagnosis; however, tests are needed to find its cause. The most common test, an EMG, measures electrical currents in your nerves and muscles, and helps diagnose PN. Different types of PN will affect these currents differently.

Many other tests are used to find the underlying causes, though this can be challenging and elusive. They include an EEG, MRI, CT scan, lumbar puncture, nerve and muscle biopsies, and blood and urine tests. Even after taking many tests, some people may still not know what's causing their PN.

## How do you prevent it?

Ways to prevent PN include a healthy diet, making sure you're taking the most effective HIV therapy, and being aware of which drugs cause PN. Since some vitamin deficiencies can cause PN, it's important to get the proper daily amounts of minerals and vitamins, especially B12 and E. Refraining from taking mega-doses of some vitamins, like B6, as well as reducing high alcohol use will also help prevent PN.

Low CD4 counts and high viral load can increase the risk for PN, so getting the best possible therapy for your HIV disease can help prevent it. This means taking HIV meds that keep your viral load undetectable and increase and sustain your CD4 counts to as high as possible. The longer this happens, the better chance your body has to control other infections and conditions like PN.

Talk to your health provider about whether any of the drugs that you currently take as well as any new drugs that she or he prescribes for you are known to cause PN. Stopping those drugs or finding alternatives to them will help prevent PN. It's also important to properly treat other medical conditions that are causing PN.

### What can help to ask about at a doctor's visit?

- Do you have enough information about me and my risks for PN? What should I do if I have more than one type of risk?
- What tests do you recommend I take to find out what's causing my PN? Why are they important?
- Am I taking drugs that cause PN? If yes, can I have the dose changed or switch to something else?
- Are there any new or experimental drugs that I could use for my PN?
- What non-medical things can I do to help my PN?
- Could I do better on a different HIV regimen?



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## How do you treat peripheral neuropathy?

Treating PN is usually focused on treating the underlying cause(s) and controlling the symptoms with the right medicines. Currently, there are few treatments for PN itself and none of them are highly effective, though new research shows promise. For some, dealing with their chronic pain may contribute to depression. So treating PN may also need to include treating depression.

There are several ways to ease or treat PN: making lifestyle changes, taking pain relievers, changing or stopping the medicines that cause PN, and taking medicines that control PN. You may need to use more than one of these to treat your PN. It also may take some time for your symptoms to improve.

Much of the research on treating PN has occurred in HIV-negative people, a good deal of it in people with diabetes. Though this information is useful, it may not address the specific health needs of people with HIV. Seeking the advice of an HIV experienced neurologist can greatly improve your outcome.

### LIFESTYLE

You can do many things yourself that may relieve your PN. Some people find that one approach is enough while others use several ways to ease their discomfort.

- **WEAR PROPER SHOES.** Tight or ill-fitting shoes can cause pain even in people without PN. So consider wearing shoes that give the proper support for your feet while still being flexible for comfort. Consult a foot doctor (podiatrist) or experienced salesperson for the best choice for you.
- **KEEP YOUR FEET COOL.** Many people with PN report that soaking their feet and hands in cold water helps reduce the pain. Consider keeping your feet and hands free of bed covers at night. Many report more pain in the evening, especially when getting them wrapped up in their covers.
- **IMPROVE YOUR DIET.** Getting enough vitamins B12 and E in your diet is important. Foods high in B12 include liver, snapper, salmon, beef, poultry, milk, eggs, shellfish, tofu and yeast. Foods with E include green leafy vegetables, carrots, nuts, oils (olive, corn, canola, safflower, sunflower), wheat germ, whole grains, and margarines made from plant oils. Consider taking supplements that provide the recommended daily amounts.
- **GET A MASSAGE.** Massaging your feet and hands increases blood flow, which can ease pain. A massage therapist, friend or even you can gently massage those areas that have pain.
- **AVOID STRAIN.** Ease foot and leg pain by not walking great distances or standing for long periods. Also, avoid repetitive tasks with your hands and fingers. On the other hand, when able, moderate walking or other activity can help improve blood flow to the feet and reduce symptoms.
- **TRY TO RELAX.** There are many different relaxation techniques and exercises. Find the ones that suit you and consider doing them more than once a day.
- **USE SUPPORT TOOLS.** Pain in the hands may prevent you from doing daily tasks, like opening jars of food or pulling up a zipper. Kitchen tools are available with easy grips as well as reachers for items on shelves. Dressing aids are also available, from long-handled shoehorns and brushes to zipper pulls and elastic shoestrings. Many of these aids that help older adults with their mobility concerns can be found in stores and online. Your doctor may have listings for where to buy these products.

### STOP THE OFFENDING DRUG(S)

If you take a medicine that's known to cause PN, your doctor may recommend stopping it, adjusting its dose, or switching it to something else. Do not stop a drug without your doctor's knowledge. Be aware that stopping an offending drug may actually make your PN worse for a short time. This occurs in about 1 of 4 people.

### PAIN RELIEVERS

Over-the-counter medicines, like ibuprofen, aspirin and acetaminophen, can help ease mild-to-moderate pain due to PN. Your health provider may recommend prescription versions for you.

### STRONGER PAIN RELIEVERS

For moderate-to-severe pain, your doctor may prescribe narcotics for short-term use. Many are available for various levels of pain, so if you have difficulty taking one then another may be better. Common side effects include nausea, vomiting, constipation, tiredness and sleepiness. For those with a history of drug addiction, taking a short-term course of these drugs should be safe, but discuss this with your doctor should you have concerns. Also, these drugs may interact with the HIV drugs you take.

## TRICYCLIC ANTIDEPRESSANTS (TCAs)

These drugs were among the first anti-depressants. They are thought to work by adjusting the balance of certain chemicals in the brain. They also inhibit certain cell receptors, which cause their many possible side effects. You and your health provider may need to try different drugs before finding the one that works best.

TCAs are usually used to treat mild-to-moderate pain, and are sometimes taken with pain relievers. Though some report that these drugs improve their symptoms, studies actually show that they're not clinically effective. The more commonly prescribed TCAs for PN include Elavil (amitriptyline), Aventyl (nortriptyline), Norpramin (desipramine) and Tofranil (imipramine). Some protease inhibitors and NNRTIs can interact with TCAs and change their blood levels. Your doctor may need to adjust the dose given the HIV meds you take.

TCAs are normally prescribed in small increasing doses to avoid side effects. This gives the body a chance to adapt to the new drug. Common side effects include dry mouth and nose, blurred vision, drowsiness, difficult urination and constipation. Other side effects may include restlessness, anxiety, nausea, memory problems, weight gain and sexual problems, among others.

## ANTICONVULSANTS

These drugs are normally used to prevent and treat seizures due to epilepsy. They work by controlling the nerve activity in the brain. Anticonvulsants are being used more often to treat other conditions like PN, and studies show some success in controlling its pain.

Several drugs are used for PN: Neurontin (gabapentin), Dilantin (phenytoin), Tegretol (carbamazepine) and Lamictal (lamotrigine), among others. You and your health provider may need to try different drugs before finding the one that works best for you.

Anticonvulsants are usually prescribed in small increasing doses to avoid side effects, giving the body a chance to adapt to the new drug. Common side effects include drowsiness, dizziness, nausea, vomiting and constipation. Other side effects may include restlessness, sleep problems, memory problems, sore joints or muscles, among many others.

## MEDICAL MARIJUANA

A 2007 study report showed that smoking medical marijuana reduced chronic pain by one-third due to PN in just over half of the participants. All smoked three marijuana cigarettes a day. Side effects included dizziness, anxiety, confusion and sedation. Medical marijuana may not be available to you as a treatment for PN since it's classified as a controlled substance.

## TOPICAL MEDICINES

Some patches and gels that are applied to the skin may be able to treat some symptoms of PN. See Research on peripheral neuropathy below for more information.

## SUPPLEMENTS

Two supplements are now being studied to treat PN. More information about both is found in Research on peripheral neuropathy below.

## ACUPUNCTURE

Some people report that acupuncture helps them managing their pain. Research has not proven this effective, including a US study that compared it to placebo. However, a person's belief in the process may be enough for her or him to get relief.

## Concerns for people over 50

In the general public, peripheral neuropathy affects people over 55 at a higher rate than others. About 3–4% of older adults are affected by some form of it. As people living with HIV age, they are more likely to suffer PN due to the length of time they live with HIV, having multiple conditions, or using HIV or other drugs that cause it. Managing PN in people with HIV can be challenging, especially in later age and later stage disease. However, with persistence, it's possible to control PN with the various medicines available today along with current studies showing hopeful results.



## Access to medicines

The medicines used to treat PN are available by prescription. Some states may cover these meds through their AIDS Drug Assistance Programs (ADAPs). To see if you're eligible for your state's ADAP and to find out if these meds are covered, contact your state ADAP, state department of health, or state Office of AIDS. Information can also be found through the AIDS Treatment Data Network at 1-800-734-7104, or visit [www.atdn.org](http://www.atdn.org) and click on "Access Project." People who lack coverage for meds can sometimes gain access to them through the manufacturers' Patient Assistance Programs. A good resource for this is [www.rxassist.org](http://www.rxassist.org), though you must sign in for the service. Another online resource is [www.pparx.org](http://www.pparx.org).

## Research on peripheral neuropathy

The likelihood that PN becomes a problem increases as people with HIV live longer. Some are faced with taking drugs that cause PN, so trying to prevent it and treat it can become a challenge for doctors and their patients.

### TOPICAL MEDICINES

One small study that used the skin gel Lidoderm (lidocaine) for PN showed that it didn't lower the pain. However, some people do use it. A larger international study is now looking at using a skin patch with capsaicin, the compound that makes chili peppers "spicy". So far, the study has showed good results of reducing pain among the volunteers.

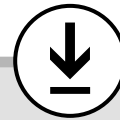
### SUPPLEMENTS

An amino acid supplement, called L-acetyl carnitine (LAC), has been studied for treating and preventing PN. In 2004, a small British study showed some evidence of less painful symptoms and nerve regrowth. Volunteers took 1,500mg LAC twice a day. Results from an older study showed that LAC eased PN symptoms over placebo. More study is needed to show its possible effectiveness.

A second supplement, uridine, may improve the function of mitochondria—the power centers inside cells. This, in turn, may reverse nerve damage. Some studies are using it to treat PN due to diabetes and so far report hopeful data. Other studies have begun in people with HIV.

### MEDICAL MARIJUANA

A 2007 study report showed that smoking medical marijuana reduced chronic pain due to PN in just over half of its 50 adult volunteers. All smoked three cigarettes a day for 5 days, either with medical marijuana or placebo. The amount of relief averaged a more than 30% reduction in pain. Side effects included dizziness, anxiety, confusion and sedation.



## the bottom line on peripheral neuropathy

- › Peripheral neuropathy affects about 1 in 3 people living with HIV.
- › There are many risk factors for PN in people with HIV, including low CD4 count, high viral load, poor nutrition, older age, later stage disease, an AIDS-defining infection, using drugs that damage nerves, and diabetes.
- › The symptoms of PN can range from mild and non-existent to severe and disabling.
- › Treating PN should include finding its underlying cause as well as relieving its symptoms.
- › It may take time and effort on you and your doctor's parts to properly diagnose and treat your condition.
- › You can make many changes in lifestyle to manage your PN symptoms.
- › Many different types of drugs are used to treat PN, though many of them interact with HIV drugs. Talk to your doctor about which is best for you.
- › Current research is showing hopeful results on a couple of new treatments for PN.