

# Peripheral neuropathy and HIV disease

In the US, *peripheral neuropathy*, or PN, is caused most often by diabetes and alcoholism. But about 1 in 3 people with HIV will develop this disease of the nerves. Though it's a common condition that affects nearly 20 million Americans (more often in older adults), PN can profoundly affect a person's quality of life.

When diagnosed and treated early, PN can often be controlled. For some, though, managing PN is challenging. It may take some time to treat your PN properly and certain treatments may not work. Even after treatment, symptoms may still persist, though probably to a lesser degree.

## What is peripheral neuropathy?

Peripheral nerves, the nerves that serve your limbs and organs, are not protected by bone like the spinal chord and brain, leaving them exposed to possible injury and infection. In general, PN is caused by damage to these nerves — to the cell body, its nerve fiber or its coating. This damage impairs your body's ability to communicate with your skin, muscles and internal organs. Normally, PN affects the toes, feet and legs first. The fingers, hands and arms can become affected as well.

## What causes it?

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

For those living with HIV, HIV itself can cause PN by destroying nerve fibers. As well, some HIV drugs — notably Zerit (stavudine, d4T) and Videx (didanosine, ddI) — and other drugs like Dapsone, INH (isoniazid), Flagyl (metronidazole), Oncovin (vincristine), Myambutol (ethambutol) and Zyvox (linezolid) can also contribute to it. Newer HIV drugs have not shown this risk, though it may take several years before it appears.

## Who is at risk?

Several risk factors put people with HIV at 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 and in older individuals.

Men and women seem to have PN at about the same rate. People at risk are those who do not get enough minerals and vitamins (especially B12, E) and or too much vitamin B6. Certain common HIV-related drugs can increase the risk for PN, as mentioned above. Using two or more of them or having any of the conditions listed above can put you at even higher risk.

## What are the symptoms?

Symptoms vary from person to person and can range from mild to severe and perhaps disabling. Sometimes PN is present even without symptoms. 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.

When people first get PN, they normally feel sensations like tingling, weakness, numbness, pinching, buzz-

## Peripheral neuropathy and HIV disease



ing 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 it as "frostbite", "pins and needles", "a lit match" or "walking on broken glass".

### How is it diagnosed?

People with HIV can have other conditions of the nervous system, so it's important to describe your symptoms correctly and sooner rather than later to improve your outcome and reduce damage to your nerves. Your doctor will base the diagnosis by talking to you about your symptoms. No actual tests are needed for it; however, tests are needed to find its cause. The most common test, an EMG, measures electrical currents in your nerves and muscles. Different types of PN will affect these currents differently.

Many other tests can be used: EEG, MRI, CT scan, spinal tap, nerve and muscle biopsies, and blood and urine

tests. However, 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 eating a healthy diet, making sure you're taking and staying on potent HIV therapy, and being aware of which drugs cause PN. It's important to get the proper daily amounts of minerals and vitamins, like B12 and E. Refraining from taking high doses of some vitamins, like B6, and reducing high alcohol use will also help. Talk to your doctor about whether any of the drugs you take are known to cause PN. Stopping those or finding others to use will help prevent PN. It's also important to properly treat other medical conditions that may cause 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 tests do you recommend I take to find out what's causing my PN, and why?
- 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?
- What non-medical things can I do

to help my PN?

- Could I do better on a different HIV regimen?

### How do you treat it?

Treating PN is usually focused on treating the underlying cause(s) and controlling its symptoms with the right medicines. There are few treatments for PN itself and none are highly effective, though new research shows promise. Treating PN may also need to include treating depression.

Much of the research has occurred in HIV-negative people, and a good deal of it in people with diabetes. Though this 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

Some people find that a single change in lifestyle is enough while others use several ways to ease their discomfort.

- **WEAR PROPER SHOES.** Tight or ill-fitting shoes can cause pain, so consider wearing shoes that give the proper support for your feet while still being flexible. Consult a foot doctor or experienced salesperson.
- **KEEP YOUR FEET COOL.** Soaking your feet and hands in cold water can help reduce the pain. Keep your feet and hands free of bed covers at night.

## Peripheral neuropathy and HIV disease

- **IMPROVE YOUR DIET.** 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 supplements.
- **GET A MASSAGE.** Massaging your feet and hands increases blood flow, which can ease pain and help you relax. A massage therapist or friend can also help.
- **AVOID STRAIN.** Ease pain by not walking great distances or standing for long periods. Avoid repetitive tasks with your hands and fingers. On the other hand, moderate walking can help improve blood flow and reduce symptoms.
- **USE SUPPORT TOOLS.** Many of the aids that help older adults with their mobility concerns can be found in stores and online. 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.

### STOP THE OFFENDING DRUG(S)

If you take a medicine that causes PN, your doctor may recommend to stop it, adjust its dose, or switch it to something else. Do not stop a drug without

your doctor's knowledge. Stopping a drug may actually make your PN worse for a short time.

### PAIN RELIEVERS

Ibuprofen, aspirin, acetaminophen and naproxen can help ease mild-to-moderate pain. Your doctor may recommend prescriptions for you.

### STRONGER PAIN RELIEVERS

For moderate-to-severe pain, narcotics may be used. Many are available for various levels of pain. Side effects can include nausea, vomiting, constipation, tiredness and sleepiness. For those with a history of drug addiction, taking a short-term course of these should be safe, but discuss this with your doctor. Also, these drugs may interact with HIV drugs.

### TRICYCLIC ANTIDEPRESSANTS

These drugs are thought to work by adjusting the balance of certain chemicals in the brain. But they also inhibit certain cell receptors, which cause their many possible side effects.

TCAs are usually used to treat mild-to-moderate pain, and are sometimes taken with pain relievers. However, studies actually show that TCAs are not clinically effective even though some people report that their symptoms improve. The more common TCAs for PN include Elavil (amitriptyline), Aventyl (nortriptyline), Norpramin (desipramine) and Tofranil

(imipramine). Some protease inhibitors and NNRTIs can change the blood levels of TCAs.

TCAs are normally given in small increasing doses to avoid side effects, giving the body a chance to adapt. Common side effects include dry mouth and nose, blurred vision, drowsiness, difficult urination and constipation, among many others.

### ANTICONVULSANTS

These drugs work by controlling the nerve activity in the brain. They're being used more often to treat other conditions like PN, and studies show some success in controlling its pain. Several are used: Lyrica (pregabalin), Neurontin (gabapentin), Dilantin (phenytoin), Tegretol (carbamazepine) and Lamictal (lamotrigine), among others.

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

### 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.

## Peripheral neuropathy and HIV disease

### 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. 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, PN affects people over 55 at a higher rate than others — in about 1 in 20. As people with HIV age, they're more likely to suffer from PN. Managing it can be challenging, especially in later age and later stage disease. However, with persistence, it's possible to control PN with the various options available.

### Where to get treatment?

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 and what meds are covered, contact your state ADAP, department of health, or Office of AIDS. Information can also

be found through 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 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 large international study is now looking at using a skin patch with *capsaicin*, the compound that makes chili peppers "spicy." Smaller studies of capsaicin in HIV-positive people have shown promising results in about 1 in 3 people who used the patch. The patch is applied for a short time and relief may last for as much as 3 months.

### 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 re-growth. Volunteers took 1,500mg LAC twice a day. Results from an older study showed that LAC eased PN symptoms over placebo. More study is still needed. It's unknown if taking the supplement LAC found in some health food stores will provide the same results.

Another supplement called uridine (NucleomaxX, not available in the US) 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 3 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.