Ask the Experts: Peripheral Neuropathy

“Over the past six months I’ve noticed a burning feeling in my feet. It’s not too bad, but it is constant. I’m worried about it. Should I mention it to my doctor? Do you have any tips on how to handle it?” —J.M., Yellowknife, NWT

Christopher Power

Neurologist, University of Alberta
Edmonton

A myth exists that peripheral neuropathy (PN) is no longer a problem for people living with HIV. However, I work in both major HIV clinics in Alberta (Edmonton and Calgary) and I see several people with PN at every clinic. PN damages the peripheral nerves (the nerves in the body, not including those of the brain and spinal cord) and causes numbness, electrical-like tingling or a painful burning sensation, usually in the feet and sometimes in the hands. It can also cause difficulty with walking and occasionally with bowel and bladder functions.

Other nerve disorders, such as carpal tunnel syndrome or sciatica, can be early indicators of PN. Contrary to what you might hear, PN is still very common among people with HIV, especially as they age and their disease progresses. People with HIV often don’t realize they have it. They frequently see me for another problem and then say something like: “My feet really hurt at night or if I’m on my feet all day. I think my shoes might be too tight.”

The good news is that most people with PN now experience mild to moderate symptoms. In the early ’90s, before antiretroviral therapy (ART), I would see people who would cut the tops off their shoes because anything touching their feet caused horrendous pain. I still occasionally see people suffering from exquisitely painful and debilitating PN but it’s far less common.

Many factors and conditions can cause PN. HIV infection itself can cause neuropathy by damaging nerve cells. You are also at greater risk of developing PN if you are tall, older than 55, have an AIDS-defining illness or your CD4 count falls below 200. People with diabetes can also develop neuropathy, so it’s important to find out if diabetes is causing your PN; if it is, work with your doctor to control your blood sugar. We also know that heavy alcohol use and poor nutrition can lead to nerve damage. Finally, syphilis can cause PN and hepatitis C virus infection can make it worse, so don’t let these conditions go untreated.

PN is also a side effect of various drugs (see interview with Danielle Gourde). If you have drug-induced neuropathy, you might be able to improve your symptoms and prevent permanent damage by seeing your doctor and changing your medication right away.

Danielle Gourde

Pharmacist, Clinique médicale l'Actuel
Montreal

Neuropathy is a side effect of the older antiretroviral drugs, sometimes called D drugs: d4T (stavudine, Zerit), ddl (didanosine, Videx) and ddC (zalcitibine, Hivid). In Canada, Hivid is no longer on the market and physicians no longer prescribe the other two unless a patient is resistant to newer antiretrovirals. Some other medications prescribed to people with HIV can cause PN as well (for example, some drugs used to treat PCP and tuberculosis). If you are concerned that you might have symptoms of PN, talk to your doctor.
The first thing we try to do, if possible, is discontinue the drug that may be to blame. At the moment, there is no cure for PN and no medication decreases numbness. For pain relief, options are limited but some drugs seem to work in some people. Some people with mild pain find that amitryptiline (Elavil) helps. This is an old antidepressant that doctors no longer prescribe for that purpose because of side effects at the antidepressant dose. We give it to patients with PN at a lower dose. They take it at night because it makes people sleepy (and many people’s PN symptoms worsen at night). People with more severe symptoms often combine it with pregabalin (Lyrica) or gabapentin (Neurontin)—pain relievers originally developed for epilepsy. The main side effects of these two drugs are drowsiness and dry mouth.

A drug called topiramate is sometimes prescribed for people with HIV and PN alone but usually for people who also have diabetes. It can cause people to lose their appetite and lose weight as a result, which can improve the diabetes of people struggling with their weight.

Opiates are sometimes dispensed for PN pain; however, we try to avoid prescribing them for long-term use as they can be addictive.

PN pain is very different from other kinds of pain, so not all pain relievers are suitable and some interact with antiretrovirals. Finally, prescription drugs are only one part of a possible plan. You and your doctor will need to figure out what works best for you.

Todd Tran

Occupational Therapist (with expertise in Pedorthics), Women’s College Hospital; Consultant, Casey House
Toronto

PN affects 30 to 67 percent of people with advanced HIV disease (people who have lived with HIV for many years or have a high viral load or a low CD4 count). I try to work with my clients’ doctors because I believe that a multidisciplinary approach ensures that clients get the best care possible.

For clients who experience more pain when they walk or stand for long periods, we recommend custom-made orthotics and/or orthopedic shoes, which relieve pressure from certain parts of the feet. For clients who have difficulty walking, I also recommend adaptive equipment, such as a cane or a walker with a seat, which allows people to sit down and offload mechanically induced foot pain. I recommend wheelchairs as a last resort for people who are not able to walk about. I want people to be mobile for as long as possible.

When people have a combination of HIV, PN and type 2 diabetes, they can develop a loss of protective sensation (LOPS) in their feet. Clients sometimes ask me, “What’s the big deal if I can’t feel?” LOPS puts people at risk for self-harm. For example, a person might walk along the floor barefoot and only realize they’ve stepped on a tack when they notice blood or the tack sticking into their foot. When this happens, the healing time may be longer for a person with HIV (due to immunosuppression) than for an HIV-negative person. And the wound might not heal adequately, which can potentially lead to serious complications. If you have LOPS, you should:

- Examine your feet daily. If you can’t bend over or see your feet, put a mirror on the ground and place your feet over it.
- Dry in between your toes after a bath or shower to prevent skin breakdown due to fungi, and wipe away flaky, dead skin in between the toes. If you can’t reach your toes, seeing a foot care nurse, chiropodist or podiatrist for regular nail and skin care is vital.
- Don’t wear outdoor shoes indoors (to avoid tracking pebbles, glass and debris inside). You may want to wear an indoor shoe to protect your feet from sharp objects, banging them against a bedpost or other injury. Always wear socks with your shoes to protect your feet from seams in the shoe, which can irritate or hurt the skin.
- When buying new shoes, always feel inside the shoes for anything that might irritate your feet.
- Consider orthopedic or accommodative footwear. (Some insurance plans cover the costs of orthopedic shoes.)
- Schedule regular checkups with your doctor or foot specialist.
Joe Dacey

Person living with HIV
Dartmouth, Nova Scotia

I was diagnosed with HIV in 1990 and I first noticed a strange tingling in my feet and hands about three years ago. My PN rapidly became so bad in my feet that I couldn’t walk any distance. My doctor is convinced that the HIV drugs I took in the past caused my disease.

When my PN started, I had a lot of pain in my feet and they felt extremely hot. Now I still have pain but my feet usually feel extremely cold. I take a low-dose, slow-release form of oxycontin four times each day. If the pain becomes excruciating, I take a faster-acting form of the drug. The drugs don’t get rid of the pain but they tone it down a little.

Aside from the meds, what helps me most with the pain is my heating pad. I rest my heels on the heating pad on my ottoman, and then I wrap a blanket around my feet and the heating pad to keep the heat in.

I’ve talked with my doctor about removing the pain receptors in my feet. But without my pain receptors, I could bump into something or break my toe and not even realize it. So, I just keep going the way I’m going. It’s about all I can do.

Fortunately, I was able to get enough money together to buy a scooter and a power wheelchair. I use the wheelchair when Access-a-Bus [door-to-door transit for people with disabilities] picks me up for my medical appointments. I can walk around my apartment but I use the power chair to go anywhere else. Typically, I feel best in the morning. On nice mornings, I spend some time outside before the pain gets too bad. I can’t wear shoes or even light socks because of the pain. In the summer, I can wear flip-flops outside but I have to be careful to not expose myself to the sun for too long because that can cause other problems due to the HIV medication I take.

Of course, it’s very uncomfortable and frustrating. The thing that keeps me going is that I look around and see that some people are much worse off than I am healthwise. I wouldn’t wish this on anyone but it would be nice to know someone else who has PN. We might be able to exchange tips. Maybe this article will get people talking and I’ll meet someone else who has PN. In the meantime, I try not to let it get to me.

Some people with PN use complementary and nutritional treatments to help their nerves recover from PN, a process that can take months or years.

- Alpha-lipoic acid—an antioxidant used to treat PN.
- B-complex vitamins—particularly vitamin B12 injections.
- Vitamin E—to help with oxygen metabolism and blood flow.
- Essential fatty acids—from evening primrose oil and cold-water fish, such as wild salmon, sardines, mackerel and anchovies.
- Acetyl-carnitine—which research has found to be helpful for treating PN. Acetyl-carnitine is available in some health food stores and L-carnitine is available by prescription.
- Acupuncture—performed by an experienced doctor of traditional Chinese medicine.
- Deep tissue massage for limbs affected by PN—to help stretch and relax muscles.
- Smoking cannabis—cannot help nerves recover, but can lessen pain for some people.

Before taking any of these, be sure to talk to your doctor about your plan for tackling PN.
Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

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