Pain, Pain, Go Away

It’s a challenge for some people with HIV. But there’s help for conquering—or at least managing—chronic pain.

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Betsy Luz Correa, 43 and diagnosed with HIV in 1993, is no slacker. The Weathersfield, Connecticut, resident has been a staffer at local Latino and LGBT agencies (“I’m not LGBT, but I’m an ally,” she says), works on social-justice causes and once loved to dance salsa, *bachata* and *cumbia*. Recently, she chatted with *POZ* by phone while a friend pedicured her. “She’s painting my nails bright red,” Correa reported. “I call them puta red!”

But Correa won’t be wearing her sexy open-toed heels to show off those hot toenails. Chronic leg pain during the past 15 years rules out such footwear. The distress has also forced her to take a leave from work and devote much of her time to finding the source of the pain, or simply staying comfortable. “It started in my legs,” she says. “If I tried to squat, they’d buckle. I needed somebody to help me get off the floor, out of a chair or in or out of bed.” Then the pain spread to her abdomen. Now, it resides in her back and below her rib cage.

Correa says she’s been to every kind of specialist and had every kind of test to determine the pain’s source, HIV-related or not. “EMGs, CT scans, MRIs, ultrasounds, you name it,” she says. “It’s all come out normal.” (Her HIV has always been well controlled, she says, adding that she recently tried a break from treatment to see if her HIV meds were causing the pain; apparently, they weren’t.) While Correa continues her efforts to pinpoint the pain, she tries to alleviate it with everything from meditation and massage to *qigong* (Chinese movement and breathing) and light stretching.

About 70 million Americans live with chronic pain. Now that HIV meds can conquer many infections and disorders that once caused physical misery, fewer HIV-positive people live in pain. But the rate is still high. There are no recent studies tracking HIV pain rates, but Mark Cichocki, RN, at the University of Michigan’s HIV/AIDS Treatment Program and the author of *Living With HIV: A Patient’s Guide*, says that 3 in 10 of the program’s roughly 600 patients live with pain. The single greatest source, he says, is HIV-related neuropathy—a nerve damage, usually in hands and feet, that causes tingling, numbness and burning pain and is related to HIV itself, certain HIV meds or both. Other common causes of ongoing discomfort include nerve pain from herpes or shingles; abdominal pain from pancreatitis, liver disease or acid reflux; migraines; and muscle or bone pain (research suggests that more people with HIV experience bone loss than do their negative peers).

“The big thing,” Cichocki says, “is to get to the root of the pain.” Although it might require special doctors and tests, finding and treating the problem often tames the pain. But if a diagnosis is not fast in coming, don’t stop there. “Pain should not be ignored or accepted,” says David Simpson, MD, who heads the Neuro-AIDS program at the Mount Sinai School of Medicine in New York City. “If your doctor won’t deal with it, find someone who will.”

Long-term pain is harmful. It weakens everything from your organs and immune system to your overall mood and energy level—even your exercise and eating habits. “You just don’t have to live with it,” says Diane Meier, MD, who heads Mount Sinai’s Center to Advance Palliative Care. (She stresses that palliative, or comfort-oriented care, isn’t just for those approaching death but for anyone living with such chronic disorders as pain, depression or fatigue.) “Pain can be treated effectively with standard analgesic [pain-quelling] regimens,” she says, “but you have to be prepared for a period of trial and error to find the right mix of meds—and a doctor willing to work with you until you get adequate relief.”

Pain is measured from 0 (none) to 10 (worst pain possible). So lowering your everyday pain level from, say, 8 down to somewhere between 2 and 5 is a goal. There are myriad pharmaceutical relievers (far too many to list all here), including non-opioids for mild pain (Tylenol, Advil, Motrin and steroids), weak opioids for moderate pain (codeine, Vicodin) and strong opioids for severe pain (morphine, fentanyl, methadone, Oxycontin). Antidepressants (like Cymbalta), anticonvulsants (like Neurontin) and topical or injectable anesthetics (like Lidocaine) can also be used. One new anesthetic, pioneered by Simpson and just approved by the FDA for herpes-related pain but also available for neuropathy, is Qutenza, a patch containing capsaicin, a chemical from the chili pepper. The patch is applied at the doc’s office and can lessen pain for up to three months. (For other ideas, see “Win the Pain Game.”)

But there are pitfalls. Opioids, for example, can be addictive. “You need to be honest with your doctor about any [substance use] history you have,” says Meier, adding that just because you have, or had, a substance problem doesn’t mean you shouldn’t take pain meds—only that you may need to sign a “pain agreement” with your doctor, promising to take only meds prescribed by him or her, as directed, and to be completely honest about any non-prescription substance use. Worried about addiction, some doctors avoid prescribing opioids. “You have to balance the risks and benefits of opioids, and doctors who don’t understand [the balance] should not be prescribing,” insists Russell Portenoy, MD, head of pain medicine and palliative care at Beth Israel Medical Center in New York City and coauthor of a recent Mayday Fund report urging better pain-management training for doctors.

Beyond meds—or in their place if, like Correa, you’re drug-averse—alternative strategies might help: acupuncture, massage, electrical spinal-cord stimulation, physical therapy and various forms of movement and meditation. “In the brain, the pain pathways are closely connected to the pathways that govern emotion,” Simpson says. “When you experience pain, there’s an emotional response, and conversely, depression can manifest as pain symptoms.” So don’t rule out therapy or support groups, either.

It’s all about learning to subdue and live with pain while aggressively seeking to lessen or eliminate it long-term. As for Correa, she’s still working on that diagnosis. She’s having a second MRI and consulting a pain specialist. Meanwhile, she gets relief from a chiropractor and from her meditation and breathing exercises. “I know how to breathe into the pain and keep my wits about me,” she says, referring to a technique that can lower her pain level from a 9 to a 6. Plus, she says, hot showers and hot tea help. “Keep it in perspective,” she advises others living with chronic misery. “Don’t get desperate and let it be the be-all, end-all of your life.”

Win the Pain Game

Hurting? These tips can help.

BUILD YOUR PAIN-FIGHTING TEAM

You need a primary-care doc who takes your pain seriously and will work with you to find drug or non-drug solutions—possibly including referral to a pain center. To find a center near you, click “Pain Clinics” at pain.com or “Patient Portal” at painmed.org. Or call the American Pain Foundation (painfoundation.org) toll-free at 888.615.PAIN. If your doctor pooh-poohs your pain (or gives up on it while you’re still hurting), find a new one!

KEEP A PAIN DIARY

Tracking your pain (on a 0 to 10 scale) throughout the day, over several days, can give you a sense of control. It can also create a picture of when your pain ebbs and flows—and it’s a great tool to bring to pain doctors. Google “Pain Diary” to find several print-and-use versions online.

TRY SIMPLE THINGS

Naps, light stretching or exercise, hot baths, hot tea, work breaks, breathing, meditation and prayer can all give you “pain breaks” throughout the day. So can your favorite dumb TV show!

BALANCE PERSISTANCE AND ACCEPTANCE

You don’t have to live with pain, but you probably can’t banish it overnight. Balance fighting pain with accepting it, because panicking just makes it worse. Do what you can do every day and let go of the rest. “There are days I get angry and depressed,” says 15-year chronic pain survivor Betsy Luz Correa, “and days I say, ‘I feel, so I know I’m alive.’”

BE SMART ABOUT USING PAIN MEDS

Pain meds can be powerful and effective long-term, but they can easily be abused, especially if you have a substance-use history. “Don’t wait to take your meds until you’re so uncomfortable you can’t function,” says Mark Cichocki, RN. “But don’t self-diagnose and self-medicate.” Get Doc’s help.

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