



Val Shaw-Lewis receives IVIg treatment at Rockyview General Hospital.

Short circuit

Neuropathy is a condition that jolts patients with electrical shocks

BY BARBARA BALFOUR

Like a match lit permanently under her left foot, the burning pain started in her big toe six years ago and rose all the way up her ankle.

Initially dismissing it as a side-effect of a previous injury, Val Shaw-Lewis waited for the pins and needles sensation to subside.

Instead, it spread to her other foot, making her feel like they were encased in concrete.

Then, along with the loss of sensation, came a loss of co-ordination, balance and mobility.

A visit to the doctor revealed she had a form of peripheral neuropathy. Involving the nerves that

relay signals from the body to the spinal cord and brain, the disease causes them to malfunction or disappear so they can no longer carry impulses. As a result, both the ability to feel and move the limbs is lost.

“Those with severe neuropathy can easily slip into a bathtub of scalding hot water without realizing they’ve just burned their body,” says Dr. Cory Toth, a neurologist studying the causes – and possible cures – of neuropathic diseases at the University of Calgary’s Department of Clinical Neurosciences.

The cruel irony of neuropathy is that it is possible to be numb and still feel pain. While the nerves cannot feel anything at the surface of the

skin, the nerves deeper below cause jarring, stabs of pain to occur 24 hours a day.

“As our nerve fibers’ electricity jump to one another, it’s like our circuitry has gone haywire, sending signals that shouldn’t be there and causing excessive sensitivity,” says Dr. Toth.

There are more than 100 different types of neuropathy, with almost as many causes. Elvis Presley had one of its variations. Johnny Cash, Mary Tyler Moore and Andy Griffith had others.

Although it affects only one to two per cent of the population, the disorder is little known and even less understood. While carpal tunnel syndrome is a very mild example of the disorder, at its worst, neuropathy can strip away the ability to speak, swallow or even breathe within a few years.

The most common cause is diabetes; other perpetrators include excessive alcohol or drug use, abnormal genetics, or a pre-existing medical problem such as an organ malfunction, or an autoimmune disorder like rheumatoid arthritis.

Even a severe vitamin deficiency can cause neuropathy. Dr. Toth recalls one patient who worked at WestJet and ate three junk food meals a day because of his fast-paced lifestyle. The lack of green salads in his diet soon caught up to him – but with the right amount of vitamins and medications, his nerves were able to regenerate to almost full recovery, says Dr. Toth.

Another 40 per cent of cases are idiopathic, meaning no one knows what caused it. In almost all cases, the disorder is not curable – the downward progression of the symptoms can only be stalled, not stopped.

Shaw-Lewis is one of these cases. The senior suffers from Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), an autoimmune disease that eats away or damages the myelin sheath, the fatty insulation that surrounds the nerves.

Think of a live wire stripped bare from its sheath and jolted by constant electrical shocks, and you might have an idea of the pain she deals with every day.

Quality of life is seriously affected, as many of the pastimes she loved had to be given up. Some of them were obvious, like ballroom dancing and aerobics. Others were activities you may not think of right away – like driving, because she couldn’t feel the pedals beneath her feet, and cuddling premature babies at her volunteer job at the hospital, because her balance was affected.

“That killed me,” she says emphatically. “You think to yourself, you’re all alone, you can’t do what you once did, and is there anyone else out there who has this?”

As is standard for more serious forms of neuropathy, Shaw-Lewis finds physical comfort in regular intravenous immunoglobulin (IVIg)

therapy. It involves an exchange with donated human plasma to help filter out the antibodies in the patient's own blood that cause damage to their nerves in the first place.

Her emotional comfort is derived from a very different source, however. When she was first diagnosed, she asked her neurologist if there was a support group in Calgary for those suffering from neuropathy.

"When he said 'no', it was like a light went on in my brain," Shaw-Lewis recalls. "I said, 'You're looking at someone who's going to get one started.'"

What started out as a one-woman show completely funded out of her own pocket evolved into

"Those with severe neuropathy can easily slip into a bathtub of scalding hot water without realizing they've just burned their body."

the Calgary Neuropathy Support Group, a forum for sufferers to meet monthly and discuss ongoing treatments and therapies.

"I have a passion about getting the word out," she says. "I do get the odd down day – don't misunderstand me. But then I say, 'snap out of it now,'" she makes an abrupt skimming motion with her hands, "and I remind myself, sometimes you have to push yourself to get things done."

Shaw-Lewis is extremely active in giving interviews to media outlets, presentations to medical students and attending conferences around the country with her neurologist, Dr. Douglas Zochodne, who, tellingly, refers to her not as his patient but as his colleague.

A professor at the U of C, Director of the Neuromuscular Clinic and consultant neurologist with the Calgary Health Region, Dr. Zochodne works with Dr. Toth in experiments attempting to discover the mysteries of nerve regeneration and the causes of diabetic neuropathy at the Hotchkiss Brain Institute.

"We are looking at what molecules will affect nerve regeneration, or what molecules we can shut down to prevent nerves from deteriorating further," says Dr. Zochodne. "The ability to regrow nerves would have widespread application across a broad spectrum of conditions and disorders." They are also experimenting to determine causes and treatments of diabetic neuropathy, one of only two such laboratories in Canada to conduct this work.

Currently Dr. Toth is investigating the link between the loss of IQ points, memory and thinking abilities in diabetic patients, due to the effects of diabetes upon the brain as well as the loss of function due to peripheral nerve dysfunction.

A molecule called RAGE, much more common in the diabetic brain than in a normal brain, causes nerve cells to shrink, lose their ability to function, and continue to live on in a dysfunctional way.

This same substance is present in the nerve cells of the peripheral system, causing damage to sensory neurons. If a way can be found to block the production of RAGE within the body, this therapy could have multiple applications for other chronic conditions such as kidney disease, blindness and stroke.

Dr. Toth is also determining if some of their recent discoveries can help in preventing the progression of ALS, or Lou Gehrig's Disease in mice that have this disease of the motor nerves.

If studies continue to show promising results in animals, Dr. Toth and Dr. Zochodne will also look at developing new meth-

ods for treating nerve disease in humans. These developments may take years, or even decades. In the meantime, the University of Calgary's Neuromuscular and ALS Clinics investigate and treats patients suffering from neuropathy, ALS and other neuromuscular disorders causing loss of sensation and paralysis.

Sue Dutchak, co-ordinator of the Neuromuscular Clinic at Foothills Medical Centre, is intimately acquainted with the personal files of the 2,000 patients who come through every year, fielding their questions or concerns, arranging for home care when appropriate, and setting them up with the rehab services they need.

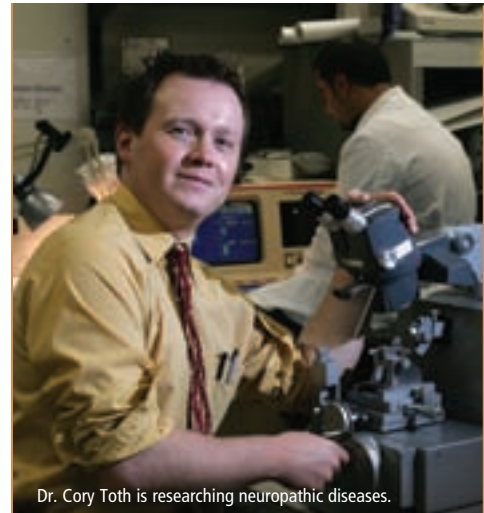
Sometimes, she just serves as an ear for those who often feel alienated by their condition.

"Many people feel very alone when learning that they have a chronic condition such as peripheral neuropathy. And when pain is a feature of their neuropathy, it's unimaginable to a healthy individual what it's like to live in constant, agonizing pain," says Dutchak.

"Gaining control is often an important step in dealing with the condition, but gaining control looks different to every individual. For some, it means learning more about their condition. For others, control comes in the form of giving voice to their daily challenges.

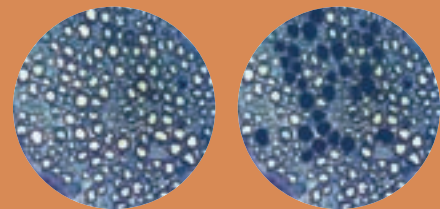
"While many patients feel alone in their suffering, hope for effective therapies or ultimately a cure is a goal that patients as well as staff of the neuromuscular clinic have in common."

Barbara Balfour is editor of Frontlines, the Calgary Health Region's staff newsletter.



Dr. Cory Toth is researching neuropathic diseases.

The photo below on the left is of a normal nerve cut on end. It contains many axons, which appear clear. These axons are the electrical wires of the nerve. The image below on the right is of a damaged nerve injured seven days before it was taken out for study. The nerve has fewer axons, and many of them appear enlarged due to swelling. Over time, the nerve will heal, although incompletely, and may leave the patient with sensory loss, pain or even weakness.



FYI

If you suffer from peripheral neuropathy, support is available. Check out these sources for more information:

Living Well with a Chronic Condition is a supportive program offering education, exercise and self-management classes for those living with a long-term illness. Call 943-2584 to register or for more information.

The Calgary Neuropathy Support Group is founded by Val Shaw-Lewis and offers monthly get-togethers, social events and guest speakers. Call 831-2187 or check www.calgarypnrs.org

The Neuromuscular Clinic can be reached at 944-4323. The clinic specializes in assessing and managing patients with disorders of peripheral nerves and muscles.