

Living with chronic pain a family affair
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Byline: Alex Frazer-Harrison
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Val Shaw-Lewis lives with pain every day of her life. So does Michael Hall. So does Louis Kovacs.

These three seniors come from different walks of life, but they all have something in common -- neuropathic pain, an invisible and as-yet incurable condition that has come to be recognized as a disease that can strike people of any age.

There are more than 100 types of neuropathy. Some are caused by other conditions such as diabetes, while others can be triggered by injury.

Shaw-Lewis began feeling tingling in her feet after suffering two major accidents in a row back in 1999.

"I was in the parking lot of the Palliser Hotel and fell over a concrete abutment and injured my knees and shoulder and broke my nose in two places," she recalls. "Three weeks later I was in a motor vehicle accident which exacerbated the previous injuries.

"Within a few months, the pain started in my left foot and transferred to the right foot. I didn't know what was happening to me. The pain was excruciating -- my feet felt like they were encased in concrete."

Shaw-Lewis was diagnosed with a form of neuropathy called Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) with anti-MAG sensory neuropathy. What this means is that her feet and legs are completely numb.

"When you're outside, you have to be careful to look where you're walking," she says. "If you can't feel a rock underfoot, you could cause your ankles to twist over. I've broken both ankles this way."

An automobile accident in 2002 sparked peripheral neuropathy in Michael Hall, 65.

"My wife hit some black ice and went into the centre median at 70 mph and rolled," he says. "We got out of that without a scratch and I thought, I've done well. Three days later, things started to happen and over the next year I noticed tingling in my toes and feet.

"I used to go walking in Prince's Island Park and that was a traditional lunch hour thing. But then I'd get pain every time I put my foot down. After a month I couldn't do it anymore, it just hurt so much."

The pain was such that Hall had to leave his regular work as a technical illustrator.

"Living with this pain is interesting because you don't exhibit any injuries to speak of," he says. "Originally everyone thought it was all in my head. Now they recognize it as a legitimate illness."

Louis Kovacs, 68, hasn't let diabetic neuropathy slow him down. Earlier this year he ran the 13.5 km Great Aloha Run marathon in Hawaii and came in 6,300th in a field of 23,000 runners.

"I cope with this problem when I'm active," he says, adding the pain started about nine years ago. "But when I sit down over an hour or two, that's when my feet start to tingle. It's almost like walking on cactus or glass or someone burning your feet with a torch."

Although linked to his diabetes, Kovacs says he also believes an accident in 1997 in which he fell 13 feet onto concrete might have also been a factor.

It was after the diagnosis that Kovacs decided to fight back by becoming as active as possible, losing weight and becoming a marathon runner.

"While you're active, you're not moping about your feet," he says. "I see people (with neuropathy) using walkers and wheelchairs. Hopefully that won't happen to me."

There is hope and support available for people with neuropathy.

Shaw-Lewis founded the Calgary (Alberta) Neuropathy Support Group four years ago to provide people with this condition an outlet for sharing information and raising public awareness.

"One of the things from my standpoint and from a number of my members, is how quality of life is affected," she says. "It not only affects your own life, it affects your partner, family and friends. My husband and I were ballroom dancers, and we still try to walk in the park when we can.

"I attend a lot of conferences (on neuropathy) and I try to pass this information along to my members. Right now our database lists about 110 people with some form of neuropathy and we regularly get up to 75 people at our meetings."

But this is the tip of the iceberg, she says, as an estimated 30,000 Calgarians of all ages experience some form of chronic pain.

Although there's no cure yet, treatments are available which vary depending on the type and severity of the neuropathy. Shaw-Lewis, for example, receives an intravenous treatment (IVIG) every month involving donated plasma which helps with her CIDP, while Hall says he has been able to enjoy increased mobility thanks to a drug called pregabalin (also known by the brand name Lyrica).

Dr. Cory Toth, Professor of Neurology at the Neuromuscular Clinic at Foothills Hospital, is leading the fight to learn more about neuropathy.

"In the past, pain has been regarded as something in your head ... many doctors are not fully aware of these conditions and often patients will go for years without a proper diagnosis," he says.

Sometimes the pain and numbness are simply seen as signs of aging, and in those cases people may not seek the help they need, Toth says.

"But things have improved and people are becoming more appreciative of (neuropathy). People are realizing there are changes happening in the spinal cord ... it's being embraced more as a disease. And there have definitely been breakthroughs in medications."

Shaw-Lewis says the best thing to do if you think you may have a form of neuropathy is to ask your family doctor for a referral to the Neuromuscular Clinic or another specialist.