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With spasticity treatment, Alexandra Arnold-Oatley no longer needs her scooter to get around.

Spasticity treatment

a life changer for PhD student

A collection of hats and scarves is stored in the basket of Alexandra Arnold-Oatley's scooter. Damp laundry is hanging off the back. If it were an exercise bike, it would be a sign of defeat. For Arnold-Oatley, it's a symbol of victory.

The scooter had been her transportation for 14 years. She counted on it to get her where she needed to go. But it couldn't help her get where she wanted to be.

Treatment at West Park Healthcare Centre's Spasticity Management Clinic changed that. Arnold-Oatley, who has lived more than 30 years with cerebral palsy (CP), has been scooter-free for two years.

Arnold-Oatley didn't learn to walk until, at age four, she had surgery on the tendons in her legs. By the time she was 11, the effects of spasticity – the severe tightening of muscles common in people with CP – had her back to see the surgeon. The discussion was not positive.

She was told plainly that in a few years, because of her misaligned gait, she would develop chronic pain. "There was a room full of therapists and clinicians and I remember saying, 'What can you do? You must be able to do something,'" Arnold-Oatley says.

The answer was equally grim, particularly for a child approaching her teens. "There's nothing we can do. This is just something you will have to live with," she recalls.

For the next decade, she did live with it. She left her home in Barrie to attend McMaster University in Hamilton for an undergraduate degree, then moved to Toronto to work on a master's. By then, her mobility issues and that predicted chronic pain had her routinely using a scooter to get around. She stayed in campus residence for the extra assistance with living. Standing to do any activities including self-care, groceries and cooking resulted in a lot of pain.

Things turned when a physician suggested she meet with West Park's Dr. Chris Boulias. Arnold-Oatley told him about her pain and was struck by his response. "He said, 'I don't just care about your spasticity, I care about your life,'" she remembers. "It was a very refreshing view. I felt optimistic meeting him and hopeful."

“Take your hand and make it into a fist. Keep it like that for one hour. There is a lot of pain associated with that.”

- Alexandra Arnold-Oatley describing spasticity

Dr. Boulias developed a personal plan of exercises and began injections of botulinum toxin to ease the spasticity. As the muscles loosened, the pain diminished and she was able to strengthen other muscles. That's when the scooter became a drying rack.

But, she points out, “It's not about whether I have to use a scooter or not. It's about the impact it has on my life.”

Arnold-Oatley now lives off campus in a downtown Toronto apartment as she works towards a PhD in neuropsychology. “I have more independence in my community,” she says. “I don't have to rely on Wheel-Trans and I can cook my own meals.”

It's that change that has made her a dedicated supporter of a rapidly-developing research program in the Spasticity Clinic. The program is starting to see results that will help

Spasticity is a debilitating condition that tightens muscles, often pulling joints into abnormal positions. It strikes people with stroke, multiple sclerosis, spinal cord injury, cerebral palsy, acquired brain injury or other neurological conditions.

more patients like Arnold-Oatley. Dr. Farooq Ismail says the latest focus is on better understanding the factors that affect spasticity; the effects of spasticity on function and balance; and how to improve the practice of injecting botulinum toxin. West Park patients, he says, have been terrific participants. “They are more than willing to roll up their sleeves to help.” That sleeve rolling is sometimes literal.

Arnold-Oatley, for example, was a test subject in a study that showed plain ice is the best topical painkiller for injections. She receives 15-20 injections in her muscles every three months. “You have to be a trooper,” she says, hesitating to describe her reaction before laughing, “When I first started, I did get a little animated.”

The study has been widely embraced by physicians around the world.

“Patients say it works,” Dr. Ismail says, “and it saves quite a bit of money.” The vapocoolants you see professional athletes use to play through pain, for example, run \$80 a bottle. A freezer and tap water are usually already on hand with no extra cost.

Arnold-Oatley has also participated in research on the strengths of personalized exercise programs, the effects of spasticity on multi-tasking and the effectiveness of hand-cycling exercises.

Although there are other treatment centres around the world, West Park is asking questions that haven't been asked before, testing anecdotal information and putting research protocols around questions that are commonly asked in the field.

One relates to the different stimuli that may affect spasticity. It might be cold weather, a simple cut, or a urinary tract infection that makes the condition worse, Dr. Ismail says. “It's been talked about by physicians treating spasticity, but it hasn't been proven.”

The results could be significant. “It's important because there may be changes in how you manage patients,”



Dr. Farooq Ismail (right) says patient support has been key to new research underway by West Park's Spasticity Management Clinic.

he says. “We may use higher doses of botulinum toxin, for instance, in the winter.”

West Park is also looking into developing best practices for managing patients on blood thinners when injections are required in a tricky part of the body. Dr. Ismail says a needle in the back of the leg, for example, could result in serious muscle issues. Researchers are surveying physicians on their approaches, looking for what works and what doesn't. “Once we publish,” he predicts, “everyone will want to post it in their offices.”

The participation of patients is key, says Dr. Ismail. “If there were no patients, there would be no research program.”

Arnold-Oatley is up for it all. “I'm always willing to participate because I've had such a positive experience,” she says. “I know that it really changes lives.”

Inspired, Arnold-Oatley remains hopeful that one day she'll be able to unplug her scooter and put it into storage, for good. ■