

'We have our life back'

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Three Multiple Sclerosis sufferers have returned from India after undergoing "life-changing" surgery that is not permitted in Canada.



Maryanne Ratz, Darren Robillard and Louanne Henry (nee Lightburn), all originally from Jaffray, travelled to the Medicity hospital in New Delhi for the Chronic Cerebrospinal Venous Insufficiency (CCSVI) treatment earlier this month.

The treatment, sometimes known as "the liberation treatment," is still very new and clinical trials have not yet been undertaken in Canada, although many sufferers are paying for treatment overseas in places like Mexico or India.

It works on the principal that MS is caused by twisted or blocked veins, and the treatment involves an angioplasty procedure where balloons are expanded inside the veins to allow blood to flow.

Family, friends and TV crews welcomed the trio back in Jaffray on Saturday.

Maryanne, 48, said she was unable to walk, talk or think clearly before the surgery.

"I had written down 24 symptoms of my MS before I went, and 22 of them have now gone," she said. "I was awake throughout the operation and when they put the balloon into my vein and opened it up it felt amazing."

Darren, 41, also said he felt immediate benefits during the surgery. "It felt like a rush when the blood started going through my veins," he said. "It was a strange feeling.

Darren was diagnosed with MS just over two years ago and has been unable to work since March.

"My biggest problem had been walking before the surgery," he said. "It felt like I was walking on hot coals. Fifty per cent of my muscles didn't work. The surgery has given me more energy and better co-ordination.

"I can walk straight now and have much more strength. And my vision is so much better. As soon as I got out of surgery I noticed how everything seemed so much more vibrant."

For Maryanne, the results of the surgery have been even more dramatic. "I have regained my balance, I can stand on one leg and turn circles, my brain doesn't feel foggy anymore," she said. "I used to drool before sometimes, and that's stopped.

"It's amazing. It's like I have a new life. I feel 200 per cent better. The doctor came to see me after surgery and said he could see I had the sparkle back in my eyes. I asked him if I could go dancing now! I'm so excited!

"I grew up on skiing in Fernie but haven't been able to do that anymore. But this year I'll be going skiing. I'll be breaking in a horse next week. I have my life back. It's just a blessing."

Louanne, 47, was not able to speak to The Free Press this week because she was in hospital with pancreas problems, unrelated to the trip to India. However her mom, Nina, said Louanne has been happy with the treatment.

"Louanne said she is feeling fine. Before she went to India she kept dropping things but that's improved.

"Her hands and legs are a lot better. She is in hospital but the doctor said it had nothing to do with the treatment."

The surgery cost \$6,500. Darren said it cost him about \$12,000 for the whole trip.

"I didn't have the money," he said. "But thankfully I had a lot of support from friends and family. There were bottle drives, a pancake breakfast, donations from the Lions, my employer and friends."

Darren said he hopes Canadian provinces will soon offer the treatment, so that MS sufferers will be able to get help in their own country.

"This treatment has definitely helped," he said. "And while Canada is not offering it to patients, they are needlessly suffering and getting worse.

"Even if it was only available here privately, it would still be better than having to travel so far."

Maryanne agrees. "The treatment I received in India was incredible. I felt like a person, not just a number. I have no regrets.

"I'm glad I had two other people going through the same thing with me. I have made two friends for life!"

- Are you considering travelling abroad for CCSVI treatment? Do you think it should be provided within Canada? Email your thoughts to editor@thefreepress.ca and we will publish a selection of stories on our letters page. Please keep your comments below 300 words and include your name and hometown.