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MS patients warn of complications after 'liberation'



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CTV.ca News Staff
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Three multiple sclerosis patients who went outside the country for the 'liberation treatment' are warning other patients to make sure they have follow-up care in case they return with complications.

One of them is longtime MS patient Jan Wexler, who went to a Bulgarian medical clinic in June. Doctors there performed an angioplasty on one of her jugular veins in her neck and the azygous vein in her chest, using a catheter-guided balloon to open up veins in the neck, in an effort to improve drainage from the brain.

During the treatment, the doctors placed a metal mesh stent inside the jugular vein to try to prop it open.

For about a week after the treatment, Wexler says she felt great, saying the weight of her symptoms lifted.

"I could sit up perfectly straight in my hospital bed, I could raise both of my arms way above my head," she remembers.

But a week later, the improvements disappeared and Wexler was more disabled than before.

She returned to Bulgaria in July, where doctors found that all the veins were now blocked more than before the first treatment and a blood clot had formed around the stent.

Now, Jan says her health has deteriorated. She is weaker than ever, she can no longer cook or drive, and she needs help bathing.

Wexler says she now regrets ever getting the treatment.

"If I knew that I was going to get worse, I would not have had it done, of course," she says.

Betty Taylor, a single mother of two from Edmonton, also travelled overseas for the treatment. She too went to Bulgaria in June where she underwent two angioplasties, one to open her azygous vein and another on a jugular vein. After her jugular vein blocked again within days of the first treatment, doctors went in again and inserted a stent.

"I noticed an immediate improvement. Overall, I had more energy I felt better and I was just looking forward to feeling, you know, a little better every day." Betty remembers.

"Right after the treatment I would say I felt 25 per cent better. Within a couple of weeks of the treatment, I definitely felt about 50 per cent better."

But she thinks either the stents have blocked with blood clots, or the veins have re-narrowed, because the benefits of the treatment are now gone.

"I feel worse than before the treatment. Yes, right now I do," she says. "I have no idea what's going on. I just know something is not right and it needs to be fixed."

The Italian surgeon who developed the "liberation treatment," Dr. Paolo Zamboni, used balloon angioplasty to open the veins. He found in his preliminary studies that about 47 per cent of patients saw their veins re-narrow.

Other vascular doctors and interventional radiologists who have started offering the

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procedure in various clinics around the world have also seen the re-narrowing. So some have been using stents to try to keep the veins from re-narrowing.

Dr. Zamboni doesn't endorse this and has discouraged the use of stents. He notes that patients who have stents inserted for other procedures usually require blood thinners and careful monitoring for blood clots afterward.

There is also the danger that the stents can migrate, pushed down from the neck toward the heart. That has already happened in one patient who was treated in California. That patient required open heart surgery to remove the stent.

While some MS patients are reporting significant, long-lasting improvements after travelling abroad for the liberation treatment, a small but growing number of serious complications are being reported.

One severely disabled Canadian MS patient who was treated in a foreign clinic using a stent developed complications and returned to the clinic for follow-up care. He died shortly after. While CTV News attempted to reach the man's family to learn more, our phone calls were not returned.

Earlier this week, Dr. Yves Robert of the Quebec College of Physicians warned that his members were hearing more of these problems.

"We are seeing patients with significant thrombosis," he told reporters in Montreal.

"It is felt that the number of complications are badly monitored internationally and likely under-reported," he said.

Most foreign clinics offer little or no follow-up after the procedure and few ensure that patients have proper treatment when they return home. Patients who run into problems are left to seek medical care at home, but some are reporting that Canadian doctors won't treat their "liberation" treatment-related complications.

Taylor says when her MS symptoms worsened, she went to her doctor to ask what to do.

"I did not get any help. I specifically did ask one doctor that I see if I could get a referral to a local vascular surgeon just to have someone to talk to about the symptoms I was experiencing. I was given the response, 'No.' I would not get a referral. 'Because I have MS, they are not entitled to be treating me in terms of vascular disease,' she said.

Francine Deshaies also developed serious clots after angioplasty treatment in Poland.

"I thought I was dying. I was really scared because it was really painful and I didn't know what to expect," she says.

She went to a hospital in Montreal where she says she was told "no vascular doctor" would see her. She eventually found a specialist who's treating her with blood thinners and she now says she feels better than ever. But she has a warning for other patients seeking treatment overseas.

"Follow up is the most important thing. When you come back you've got to see a doctor. If you don't have a doctor or follow-up, you better not go. If you have a problem, you are done," she says.

Earlier, this week, doctors in Quebec discouraged patients from seeking the treatment overseas until formal studies are completed. But the doctors say that given the possibility of complications of blood clots, patients who choose to go abroad will get follow-up care.

The message from doctors in other provinces isn't clear.

Meanwhile, Taylor is booked for another procedure in November where she hopes an American doctor will deal with her complications and give her a lasting improvement.

Wexler is also hoping to find a way to deal with her situation at a clinic in California. She still believes the treatment will have merit for many of those with MS. But she has her own advice for MS patients eager to get the endovascular treatment and are willing to travel anywhere for it.

"I would say if you can wait until there is more out there, because you don't want to get worse. That's the thing," she says.

With a report from CTV medical specialist Avis Favaro and producer Elizabeth St. Philip

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