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Ont. man dies after MS vein opening

Last Updated: Thursday, November 18, 2010 | 10:18 PM ET Comments 421Recommend 246 CBC News



Multiple sclerosis

patient Mahir Mostic, shown with his girlfriend, Bedrana Jelin, died on Oct. 19, one day after doctors Costa Rica tried to dissolve a blood-clot complication (Bedrana Jelin)An Ontario man with multiple sclerosis died of complications after a controversial treatment in Costa Rica to open up his neck veins, CBC News has learned.

Mahir Mostic, 35, of St. Catharines died on Oct. 19, one day after doctors in the Central American country tried to dissolve a blood-clot complication.

YOUR VOICE:

http://www.cbc.ca/health/story/2010/11/18/multiple-sclerosis-vein-death-costa-rica-mostic.html?r...

Do you know anyone who has undergone this vein-opening procedure for MS? Share your stories at yournews@cbc.ca.

"We didn't find exactly what happened with Mahir, but I mean it was very terrible story for us," vascular surgeon Dr. Marcial Fallas of Clinica Biblica in San Jose said Thursday.

"He was a person that was looking [for] some way to improve his life. He found that for a short period of time his life improved."

After Mostic paid \$30,000 US to go to Costa Rica for treatment in late June, he was operated on three times to have a mesh stent inserted to prop open a vein in his neck.

"He started feeling better and got his energy back," his girlfriend, Bedrana Jelin, said from Visoko, Bosnia-



Herzegovina.

Mahir Mostic's MS symptoms improved after his

neck veins were opened, but then worsened with fatal blood clot complications, his doctor in Costa Rica said. (Bedrana Jelin)

But his MS symptoms started getting worse and a blood clot formed around the stent in the vein, Fallas said. An ultrasound showed that the vein was 80 per cent blocked.

Mostic was disappointed and desperate. His friends and loved ones raised another \$8,000 US to send him back to Costa Rica after they had trouble getting a specialist to see him in Canada.

"They didn't want to touch him because he was done outside of Canada," Jelin said.

Mostic flew back to Costa Rica for treatment, but died in hospital there after doctors tried to dissolve the clot using powerful medication that Fallas thinks triggered internal bleeding.

Fallas said his clinic normally doesn't use stents because they are considered risky. But he said Mostic was willing to take the risk.

Unable to walk

Mostic had been diagnosed with a fast-moving type of multiple sclerosis three years ago. When he first sought the vein-opening procedure, he hadn't walked for 18 months.

Angioplasty, inflating small balloons to open up arteries, is commonly done for heart patients but is not an approved procedure for unblocking neck veins in MS patients in Canada.

A blood clot in the vein might be more dangerous to fix than to leave alone, said Dr. Barry Rubin, the head of vascular surgery at Toronto's University Health Network.

"Since veins have a remarkable ability to grow in other locations if one of the veins is blocked, generally it's extremely safe to just put the patient on blood thinners to try and prevent the clot from extending or breaking off into the lungs, and just waiting," said Rubin, who is also a professor of surgery at the University of Toronto.



Dr. Marcial Fallas treated Canadian Mahir Mostic in Costa Rica. (Passport

Medical)

"You don't have to go in and dissolve the clot once it's formed, if it's in a vein."

Rubin said Mostic isn't the first case of a serious complication in an MS patient who has sought treatment outside Canada. Last week, he treated a woman who had the vein procedure in Mexico.

"We found extensive clotting in the left arm reaching into the chest veins, and some of the clots had broken off and travelled to her lungs, which is called a pulmonary embolus, which is life threatening, potentially lifethreatening complication."

Dr. Paulo Zamboni of Italy is a leading proponent of treating multiple sclerosis with angioplasty. His therapy is based on an unproven theory, known as chronic cerebrospinal venous insufficiency (CCSVI), that blocked veins in the neck or spine contribute to MS.

In April, Zamboni warned patients attending the American Academy of Neurology's annual meeting in Toronto against using stents — small mesh coils — because of the high risk of the stents moving and lack of knowledge about their long-term effects.

In Canada and the U.S., seven research studies are underway to test for vein narrowing in people with MS compared with people without MS.

"Something has to be done because other people are suffering," Jelin said. "And something has to be done because it's not fair I lost someone very close to me."

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country cat wrote:Posted 2010/11/20

at 6:03 AM ETI have been quietly reading the post here for a couple of days now.

I have come to the conclusion that many people need to go back to high school and learn the difference between a vein and an artery. Or perhaps read and research before they make a post.

I have MS. I was diagnosed 2 years ago but have probably been living with it for well over 10 years. Yes I take \$18,000 worth of Copaxone per year plus a couple other medications bringing the total over \$20K. I lead a perfectly normal life. I take my dogs on long walks (yes even in the heat of summer), garden, work etc etc. So normal in fact some people don't believe I have MS. I refuse to let MS rule my life. When my doctor told me I had MS, she took it harder then I did. I told her, I have 2 choices, crawl into bed and cry..or get on with my life. I choose to get on with my life.

My husband and I have done a great deal of reading about the "liberation" treatment. Would I fly off and have it done..the answer would be a firm NO. Nor would other people I know with more severe forms of MS have it done. The more we read about it the more questions we have. Once there are larger studies completed maybe. But then again, with so many people without MS having the blocked veins, the waiting lists would be very very long. For it may come as a surprise to several posters here that the blocked veins have been found in people without MS too.

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present10s wrote:Posted 2010/11/20

at 4:58 AM ETHe took a risk that he was aware of and it didn't go wel for him. My condolences. Good for him for trying. I personally don't think that surgery is the answer for this or many other conditions, but I would not stop informed people from taking a chance if they wish to do so. I would try other alternatives, like traditional Chinese medicine or another non-invasive approach.

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acrolein wrote: Posted 2010/11/19

at 11:39 PM ETThird world countries have outstanding hospital care my 6 year experience in Thailand was better than any care I received in Canada up until 3 months ago. Some of the greatest discoveries in the medical fields originated in places other than North America. The first heart transplant was accomplished in what I would call a third world country South Africa.

Its impossible to practice these procedures on animals so unfortunately there will be a human tolls before there is a cure for M.S. I have always questioned how many lives where shortened before Christen Bernard perfected the heart transplant and who they experimented on?

- <u>2</u> <u>2</u>

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tina'spal wrote:Posted 2010/11/19

at 11:24 PM ETDear Readers:

I am really appalled at this poor mans tragic end. The fact that he and now so many others have felt compelled to travel to far flung cities for treatment is in itself a travesty.

I have a very intimate knowledge of MS myself. I was diagnosed five years ago and know that to date there is nothing that will cure me. I must expect a steady decline. When I first had interferon drugs prescribed, they said I could expect 50% fewer attacks/symptom with the drugs. They now figure its more likely 30% fewer attacks/symptoms.

My younger sister had a severe form of MS and did not have a drug plan. She was in wheelchair in under a year. She became bedridden and died after 12 years of suffering. The drugs are hugely expensive- \$400 for each weekly shot, which you take indefinitely. Hardly a good answer. Do we need something better? Yes! But I am afraid to try this invasive and little understood CCSVI treatment. I am being pressured by family, friends and aquaintances to sign right up for CCSVI and do it as soon as possible. Believe me, I am very interested in getting better, but I know that with a compromised immune system and a generally weakened physical condition many MS patients (myself included) are risking our lives such as they are, by rushing in to have this procedure. There are so many of us that are battling this demon that shortcircuits our nervous system and destroys us from the inside out. We need encouragement and support not pressure and worry. I would love to see the MS Society actually provide for things like specialised physiotherapy, family counselling and practical support like homemaker help and the like. Thank you CBC for giving us the public spotlight and allowing others to understand a little more about MS. --- name withheld pls

- <u>5</u> 2

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asdf fu wrote: Posted 2010/11/19

at 6:47 PM ETIt's amazing how many people comment without reading the article. Two points mentioned by article but frequently overlooked among those critical of the Canadian medical system:

In Canada and the US there are 7 studies under way about the vein-narrowing hypothesis. (Let's find out if the MS sufferers actually have narrowed veins in comparison with the rest of the pop. Let's find out if that is the cause before we endorse risky 'solutions');

Secondly, the article indicates that the treatment for the clot was riskier than the clot, ie., "Since veins have a remarkable ability to grow in other locations if one of the veins is blocked, generally it's extremely safe to just put the patient on blood thinners to try and prevent the clot from extending or breaking off into the lungs, and just

http://www.cbc.ca/health/story/2010/11/18/multiple-sclerosis-vein-death-costa-rica-mostic.html?r...

waiting," said Rubin, who is also a professor of surgery at the University of Toronto". So the Costa-Rican surgeons engaged in two risky procedures. We can't then blame our medical system for not following that path. If anyone deserves criticism it's the Costa Rican doctors who are exploiting the desparate victims. Might as well sell them Shark cartilage, too.

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