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# Details emerge about man who died after MS therapy



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CTV.ca News Staff  
Date: Fri. Nov. 19 2010 9:44 PM ET

Details are now coming to light about the death of an Ontario multiple sclerosis patient who travelled to Costa Rica for a form of the so-called "liberation therapy."

CTV's medical specialist Avis Favaro, who was the first to report on the controversial treatment and the theory behind it, reported on the Niagara Falls, Ont., man's death last week. At the time, the man's family was not yet ready to talk.

But it is now known that the man's name was Mahir Mistic. The 35-year-old had travelled to the Clinica Biblica hospital in San Jose, Costa Rica in June, seeking the controversial treatment. After his MS symptoms worsened, he returned to Costa Rica where he died, on Oct. 19.

The man's death underscores the confusion surrounding the controversial procedure, says an avowed advocate of the procedure.

Barrie Ont.-based vascular surgeon Dr. Sandy McDonald believes in the potential of "liberation therapy," but says the procedure Mistic underwent was very different from the one devised by Italian researcher Dr. Paolo Zamboni.

Based on a hypothesis that MS is a vascular disease caused by blocked or twisted veins in the chest and neck -- a condition he calls CCSVI -- Zamboni's technique uses balloon angioplasty to widen neck veins and increase blood flow from the brain.

After consulting with the doctor who did Mistic's procedure, Dr. McDonald said it was "nowhere near what Dr. Zamboni describes" because doctors inserted into one of the man's veins a stent, which is a small metal tube designed to keep a blocked vein open

"A procedure was done on one day, and the next day they had a sub-optimal result, so they then stented it," McDonald said.

That appeared to restore Mistic's bloodflow, and he was sent back to Canada. But when his symptoms worsened he was rushed by ambulance to St. Catharines General Hospital. A blood clot had formed around the stent, but he wasn't treated for his complications at that time.

The hospital declined comment on the case.

In October, Mistic returned to Clinica Biblica in Costa Rica seeking treatment. A clot-busting drug was injected into the stent, but Mistic died the next day.

### New theory

Zamboni first published his findings about the CCSVI theory in 2009. They flew in the face of the conventional belief that MS is an autoimmune disorder and gave hope to those who have been told there is no cure.

But on Friday, Zamboni said he was deeply saddened by Mistic's death.

"This is really terrible news for me," Zamboni told CTV News.

He's also worried that some clinics will continue to promote the use of metal stents, and that patients who develop complications from the procedure may not receive critical follow-up care.

### Photos



Mahir Mistic travelled to the Clinica Biblica hospital in San Jose, Costa Rica in June, seeking treatment for multiple sclerosis. After his symptoms worsened, the 35-year-old returned to Costa Rica where he died on Oct. 19.

### CTV News Video

**CTV National News: Avis Favaro on the treatment**  
It is not approved in Canada but many Canadians are seeking the controversial treatment for multiple sclerosis, known as the Liberation Treatment, overseas. Complications have arisen and one Canadian has already died. The man who pioneered this treatment speaks out.

**CTV Ottawa: Norman Fetterley on the reaction**  
A man from the Niagara region of Ontario has died due to complications related to his undergoing the 'liberation treatment' overseas. Medical officials are now taking a closer look at the controversial treatment.

**CTV Southwestern Ontario: Janine Grespan**  
An Ontario MS patient who travelled to Costa Rica for 'Liberation Therapy' has died following complications.

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The research paper he wrote "always recommended not to use stents in the jugular vein, so what was performed is not the methodology that we proposed," he said.

The new "liberation treatment" procedure has not been approved yet in Canada, leaving MS patients seeking relief both desperate and confused.

"The problem with all of this is that there has not been a good randomized, controlled, double-blinded study that says it's either effective or ineffective," McDonald explained. "Nor has there been a trial done that assesses what the risks are or aren't."

Based on advice from the Canadian Institutes of Health Research, and with the support of the MS Society of Canada, Ottawa has announced that it will not fund further clinical trials beyond the ones that are already underway.

Researchers in Canada and the U.S. are nevertheless studying Zamboni's hypothesis -- called chronic cerebro-spinal venous insufficiency, or CCSVI. And Saskatchewan has declared its intention to bankroll clinical trials when researchers are ready.

In the meantime, the MS Society is pleading with medical professionals to help ensure that patients who develop complications from the treatment are able to get the care they need.

"The MS Society believes people with MS who have travelled outside of Canada to receive CCSVI treatment should be allowed post-treatment care and follow-up from the health care system," it said in a statement to CTV News on Friday.

"We feel the health of the individual returning from outside of Canada is critically important."

Between 55,000 and 75,000 Canadians have MS, making the country among the most affected in the world.

*With a report from CTV's Medical Specialist Avis Favaro*

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- Anne** said  
36 71

Although I feel for these people who are desperate to find some relief from their symptoms, Health Canada has not approved this technique for a variety of reasons. This type of complication is obviously one of them. Spending great amounts of money on questionable health care in a foreign country is not the answer. This Liberation Therapy assumes that the blocked vascular system is the cause of MS. What if it is just a symptom?
- Terry** said  
44 15

I am so sorry for this family. I can understand why people who have MS will go to any lengths to get a cure. However I understand this procedure was not what the Italian Dr invented. So much money spent and in the end it didnt help him. There needs to be more research done yet before the treatment is approved in Canada. When there is a problem after the patient returns to Canada, Drs here arent going to interfere as the procedure wasnt done here and should something go wrong they will eventually be sued.
- dwayne in da peg** said  
69 2

Glad Sask. is going to bankroll the study once reasearchers are ready to go. Someone needs to either prove or disprove the science.
- Gus** said  
60 25











To not allow the research/trials into this is criminal on the part of Health Canada. What if you had MS? Would you not want to do trials on something like this? To prove or disprove it?















Canada is the most effected country per capita for MS in the world. We should be leaders in research for a cure!



















Why is it the gov't can find money for things like new fighter-jets but not health care?

We should all be up in arms about this...Health Canada not funding this is criminal.
- Julie in Toronto** said  
50 17

The question that needs to be asked is why do Canadians have to travel abroad to get what appears to be a promising treatment option for MS. Health Canada should have clinical studies going on right now to determine the efficacy of this treatmnet. The MS society gave a lousy \$1 million dollars for the study of this therapy. What the heck are they doing with the rest of the money. It is an absolute tragedy that people need to go abroad to have this surgery. We need to have studies now. Health Canada dn the MS society should be all over this therapy. IT si sbasically the closest thing we have to a cure. Whether it relieves symptoms or tackles the underlying cause, if it makes an MS patient walk again, then I say fund the damn surgery and fast track clinical trials.

<p><b>hathomas</b> said 66   4</p>	<p>No one is claiming that this procedure is a cure for MS, or that the restricted blood flow is the cause. What is claimed it that the MS patients who had the procedure done exactly as Dr. Paolo Zamboni developed, have seen marked improvement in their quality of life. People are assuming that it is a cure when it has never been claimed as such.</p> <p>Weather or not it is the cause or the cure for MS is not the discussion here. Should anyone suffer from the effects of a disease when there is a treatment that will improve their quality of life. To lump a different procedure which was carried out poorly and from the article was then again improperly treated for the complications, is irresponsible. The problem here is that drug companies make no money off of this procedure that improves life quality and because it was not discovered by the leading researchers has been dismissed as a cure.</p> <p>I repeat it has never been claimed to be a cure by its discover, it improves the quality of life for MS suffers. Why are so many against these folks regaining some sort of quality of life.</p>
<p><b>Judy Filipkowski</b> said 46   6</p>	<p>We are missing the point here. Please listen carefully to Dr McDonald. The person who died was denied care in Canada following his procedure. It has happened before and it will happen again until someone has the courage to do a paper trail every time they go to seek care for a problem, be it potential blood clot from CCSVI treatment, breast enhancement or any other condition. We have the technology to look after clots at Canadian Hospitals. What is interesting is we do not have the technology to stop the progression of MS in Canada. We are on the right track with CCSVI but occasionally we need follow-up care to get it right!</p>
<p><b>Peter</b> said 59   2</p>	<p>I have had the liberation treatment done according to Dr. Zamboni's Directives. So far the changes from before and after are unbelievable, a miracle. I am extremely disappointed that by and large the medical profession in Canada seems to focus on the negative aspects of the treatment and is attempting by any means possible to discredit the procedure. Meanwhile, those of us who suffer from MS have no means at our disposal to alleviate the symptoms and achieve a comfortable life style. I know the procedure is new and unique, but it seems that control of how we are treated for MS or CCSVI is being thwarted and the only thing available is Drugs that may or may not help but nothing is said about how they are used and their results.</p>
<p><b>Nancy from Montreal</b> said 32   3</p>	<p>What is so terribly sad about all this is that Canada is not doing anything much to test Zamboni's procedure and that leaves patients having to go to other countries at great expense. I know several people with MS and it's a horrible disease. When there is nothing in the way of hope offered, people so debilitated will jump at a chance, any chance. Add to this that when these patients come home, they can't get help from our medical establishment. That doesn't make sense. This man died because he opted for a dangerous alternative procedure and was told of the risks. And came home and couldn't get help. Yes, other people have had complications. This is horrible. But this is not unheard of with any invasive procedure. Check the medical stats on people who have died in hospital here or just after leaving hospital after an invasive procedure and you'll find there is no invasive procedure that is a 100% guaranteed success. The best option is to offer Canadian patients Zamboni's procedure in Canada, which has been tested quite a bit around the world. The procedure has helped some people-- I have a friend who went to Poland for the treatment and it's helped her MS symptoms considerably.</p>
<p><b>Joan Ofstie</b> said 36   1</p>	<p>If he had been offered follow up treatment here in Canada (Ontario) maybe he would still be alive. Many other people go out of country for various surgery's and are they refused follow up? Alberta has just stated that they will not refuse follow up. In reply to one of the comments - You don't know what lengths you will go to until you actually experience multiple sclerosis for your self. Have you ever had a charlie horse? Well try having that but worse constantly for the rest of your life and not only in your calf. Or burning pain you can hardly stand that won't go away day in day out for the rest of your life. ect ect. Painkillers won't even touch the pain. And you wonder why ms people are desperate for even a bit of relief and that is also why there are so many suicides with this disease. Canada should offer the treatment here where patients have followup because they are going to continue to go out of Country. There are risks. How many heart patients that have angioplasty in Canada? Did they ALL live? There are going to be some complications given the huge numbers that are getting the treatment. So Canada should be doing follow up.</p>
<p><b>mspatient</b> said</p>	<p>Anne, stenting is common as the article says, but Canada not only refuses to do the procedure but also refuses the</p>

<p>36   1</p>	<p>followup. As someone who has had the procedure, and as do many others, we recognize Canada's rigid stance. MS sufferers also recognize that the disease will slowly rob them of their independence, gradually reduce physical capabilities to the point that we can no longer care for ourselves. Where we become totally dependant just to continue living. It is a slow torture. There can be pain. Unlike another horrible disease, cancer, with MS you do not regain functionality once it is lost.</p> <p>Canada has refused to look into this treatment. The "experts" have very quickly become the "enemy" due to their perceived arrogance. From the sufferers point of view these experts have no proof that this treatment doesn't work. They want us to blindly believe them, but they have no study or procedural evidence to support their position. MS sufferers are desperate for good news. People get this procedure done and they feel better.</p> <p>Who cares if is only symptomatic, I personally spend 3200 every four weeks, 40,000 per year to treat symptoms using the drugs prescribed by our experts. One of those drugs has a side effect that could be fatal.</p> <p>The question to ask in this man case is, was he denied followup care in Canada? If he was, is that denial of service systemic? Did it come from a government directive, a hospital directive or simply the attending physician? As a Canadian taxpayers, who pays for the healthcare system and as a recipients of its services, we had better hope he was not denied treatment.</p>
<p><b>valoispq</b> said 26   3</p>	<p>For Terry - Well that's the problem, they (gov't and the MS society)refuse to have research done. When they finally see the light and ok the studies it will be another bunch of years before it is available to the public. Big time waste for those who are suffering from MS. The stand off against this research makes me sick and I'm sure it is all about \$, all going to neuro clinics, meds etc.. and they aren't going to share with vascular.</p>
<p><b>Mike</b> said 25   1</p>	<p>I feel Liberation Therapy should be approved and done in Canada. yes there are going to be people who die during or after the surgery but what surgery come with out risks and how many people die on the table with operations that have been done for years. Not every patient will survive. Liberation Therapy seems to be working for MS patients and if these people want to have Liberation Therapy in the hopes that it gives a much better life then I say they should be able to get it in Canada</p>
<p><b>Sarah</b> said 11   14</p>	<p>As someone in my late 20's recently diagnosed with MS. I can certainly understand why people want this so bad. But, I really think all the studies should be finished here first before heading to other countries on nothing but hope! I personally know two people who have gone and had this done. Both had symptoms disappear for a few months, but everything came back. I hope the government keeps looking into this, but I won't be one of the ones in line to go to another country.</p>
<p><b>Pam</b> said 12   2</p>	<p>i feel bad for this guy. he tried everything to get some relief from his symptoms.health canada won't approve of this because the government itself would lose out on a lot of money if this was a cure. the stent i agree shouldn't be used. once the vein opens up where's the stent suppose to go? to the heart. the balloon should be the only thing used.as for research, how is anyone suppose to do the research on this in canada if they banned anyone who has ms from getting it done? keep in mind this is a surgery they perform every single day on people that have had strokes and heart attacks.</p>
<p><b>Dennis R</b> said 19   9</p>	<p>Just another case where our Governments leave us out in the cold and refuse to help un in our hours of need.</p> <p>All that is needed is to have those people wanting the procedure done sign a release to stop all cases of suing should it not turn out good.</p> <p>This poor man had to travel twice to Costa Rica and to get a treatment and to die in a country not of his citizenship because his country refuses to help him, he was given a treatment different than that developed by Dr. Paolo Zamboni whic would not have happened here in Canada were it done here.</p> <p>A terrible waste of life thanks to our Governments who wouldn't even try to help him!!!</p>
<p><b>Lynn</b> said 17   3</p>	<p>This whole thing with the MS treatment reminds me of what the Australian Nurse Sister Elizabeth Kenny had to go through with her treatment for the after effects of Polio (do a search on it). How many more people have to die from either going to questionable clinics overseas or from</p>

	<p>running out of time waiting before this procedure gains approval. Same type of stubborn people in charge just a different generation. Some things never change.</p>
<p><b>Laurie</b> said 21  </p>	<p>I have also heard of others MS patients who have considerably positive results ...so the stories of those with complications such as this may be giving a misconception of the results of treatment overall. There are a lot of people who have bad complications from vaccines but that does not stop the administration of vaccines because of the overall benefit. Canada should be offering this procedure to MS patients at least until good data can be obtained on its benefits.</p>
<p><b>schpid</b> said 9  </p>	<p>And if those trials proved to kill more people than it helped you would be screaming at the Government for compensation. Somehow it would all be Stephen Harper's fault and a multi-million dollar inquiry would be launched. Maybe, just maybe flying after fooling around with veins and arteries wasn't such a good idea either. My condolences to the family.</p>
<p><b>Lory in Calgary</b> said 32  </p>	<p>I can smoke, drink and take street drugs and show up at emergency and they will work on me! Go out the country for a medical procedure and they refuse treatment? I would sue the medical system</p>
<p><b>brenda</b> said 1  </p>	<p>I have a nephew that has m.s which was diagnosed at 16 yrs old hmmm why all of a sudden all these Canadians North Americans getting this maybe further investigations are in order perhaps something to do with the hep"B" vaccine ouch I have been researching this and also terett syndrome. Now they know darn well the vaccines are making people sick...PEOPLE dig a little just like the chemtrails OUR government is killing us so do you think they really want to find a cure when they are trying to illiminate the population WAKE UP!!!!</p>
<p><b>Bonnie White</b> said 23  </p>	<p>Thank you for your news report on MS treatment. My daughter had the treatment done in San Diego and has experienced very positive results. I think your news report should have stressed that most people do not get a stent in their vein. This is a much more complicated procedure. Most patients just have the narrowing of the vein opened. The complication this man experienced appears to have come from the stent procedure not the vein opening. I do believe this treatment should be offered in Canada, even if it is not covered by the medical plan.</p>
<p><b>Julie in Toronto</b> said 26  </p>	<p>Brenda, with all due respect, you say nothing of substance. Nothing that is worth while reading. The interweb is full of crap telling you what you want to hear. Vaccines have NEVER been proven by ANY clinical trial to cause ANY of the problems you blathering on about. Perhaps you should read the real science before your pour over some mis-guided, scientifically illiterate web site that tells you vaccines are killing us all. I'm sick of people who don't take vaccines perpetuating this crap. What would life be like if we didn't have the vaccines. I bet you would complain then. The reason diseases are becoming so much more prevalent these days, is down to the fact that we are much, much better at diagnosing them. So, why don't you pour yourself a cup of tea and read the Lancet for a change., instead of vaccinesareevil.com. That should provide you with some real facts on which to base your arguments.</p>
<p><b>Pat</b> said 17  </p>	<p>I'm for the treatment big time, but my problem is with Health Canada taking on a massive undertaking like this. The feds spend 10% of the Canada's GDP (\$150 billion) on health care (and that's not including provincial spending). This has got us stuck in a situation where we're still paying for people to get a new nose or a new gender, but we can't afford to take on new research and procedures like this. Someone's really getting the short end of the stick here.</p>
<p><b>Margie</b> said 15  </p>	<p>In a perfect Canda, there would be enough money in the Health Care System to fund every piece of research and every procedure that 34,000,000 people want. I don't know what the price tag would be for that to happen, but I don't think Canadians can afford the tax bill for it.</p>
<p><b>tom in north bay</b> said 24  </p>	<p>I love how CANADA loves to report on how this doesnt work!! TELL that to my sister who suffers from MS. I encourage everyone in Canada who supports the MS society to halt all donations, as our family has... Until CANADA gets its head out of its ass, and stops forcing citizens to go elsewhere for LIBERATION....</p>

<p><b>Mathieu</b> said 11   5</p>	<p>@Gus If you re-read the article you might actually understand correctly. Health Canada is not banning research in this subject, it is simply not giving additional funding for it. Those who already have the funding probably wont loose it and those who really want to research this can still do it at their own risks/cost. In my mind, something this controversial shouldn't get all the research funding when other diseases have far less controversial nearly ready solutions. Dont get me wrong, I still do believe that they should get funding. All im saying is that when they give out funding, they have to decide between group A with disease x or group B with disease y... personally i would choose the group i think the funding would result in a cure for.</p>
<p><b>Albertaboy111</b> said 10   3</p>	<p>For the record, back in 2002 it was discovered that air travel is a very risky thing to undertake for someone with a blood clot, and that air travel itself can cause the clot to kill someone. Yet this man was forced to fly to get his clot fixed, as Dr.'s here refused to give him anti-clotting agents. On another news website one "doctor" was quoted as saying new veins were grown to circumvent another if their was a clot. Not sure if that is true, but that sounds very suspect as I have never heard anything in regards to that ever. Maybe provide an example? He is saying humans regrow jugular veins if they are blocked. I say prove it. That being said, stents are dangerous, and until more research and development is done in creating a safe vein stent, only the angioplasty should be done.</p>
<p><b>Cartmell</b> said 14   1</p>	<p>In response to Anne's question, "This Liberation Therapy assumes that the blocked vascular system is the cause of MS. What if it is just a symptom?"  That is a reasonable question to ask. In my opinion (I am not a medical professional yet) it is logical to treat the cardiovascular problem whether it is the etiology or a symptom.</p>
<p><b>Ed Moon</b> said 22   1</p>	<p>The effectiveness of surgery is never proven by double-blinded studies, because double-blinded studies are not possible with surgery. In a double-blinded study, neither the patient nor the medical professionals having contact with the patient know if the patient is getting the real treatment or a placebo treatment. So while double-blinded studies are possible for drugs, they are never possible for surgeries.</p>

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I am lucky to get in to see the doctor within 2 weeks, and that is only if they aren't on vacation. and many after-hour clinics are not any better. You go in minutes after they open and they are so full that they are not taking any more people for the night... then there is trying to find a doctor if you don't have one... good luck finding anyone who will take you.

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