

'MS experts in Britain have to open their minds'

Last July, we reported on the battle by MS sufferer Mark Walker to have a controversial new treatment not recognised in Britain. Here, he tells how his condition has improved since having it abroad .



Mark Walker has undergone controversial treatment abroad in the hope that it will help alleviate his symptoms caused by MS Photo: John Lawrence
By Mark Walker 7:00AM GMT 07 Mar 2011

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My wife's reaction when she touched my feet on July 1 2010 was unexpected but very welcome. "They're the same temperature and nearly the same colour," Natasha announced excitedly. I should explain that my right foot has felt cold to the touch and been purplish in appearance for many years.

The day before, I had undergone a controversial treatment at a clinic in Athens and this was tantalising evidence that something had changed in my body as a result.

I am 51 years old and I have multiple sclerosis (MS). The first symptom – double vision lasting several weeks – developed in November 1991, although I did not receive a definitive diagnosis until April 1997. By 2000, I had accumulating symptoms including numbness, balance and bladder problems and a general feeling that, while it might not be yet apparent to my friends, MS was slowing me down in every way.

In January 2003, I was hit by physical and mental fatigue so debilitating that I could hardly get out of bed. I was forced to give up my much-loved job as a management consultant with IBM, something that left me depressed. I have never recovered sufficiently to return to work. Despite treatment with conventional drugs and therapies, my MS progressed steadily, with mobility on my right side increasingly impaired, and I have had several serious relapses when symptoms have

increased in severity. As a qualified pharmacist, I have used my scientific knowledge to research the disease and its management thoroughly. I am what doctors call an “expert patient”. After 20 years of living with MS, I am willing to try any safe, logical therapy.

It was in October 2009 that I first heard about Professor Paolo Zamboni, director of the Centre for Vascular Diseases at the University of Ferrara in Italy. In 2005, his wife Elena was diagnosed with MS, and he embarked on a personal mission to discover everything he could about the disease, from medical literature dating back 100 years to the use of state-of-the-art body scanning techniques.

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He concluded that the MS was, in part, a vascular disease caused by restricted, blocked, malformed or twisted veins or vein valves in the neck and trunk. A small clinical study appeared to back his claims. He named the syndrome “chronic cerebrospinal venous insufficiency” (CCSVI – see box) and set about developing treatment to unblock – or “de-stenose” – the veins so that healthy blood flow was restored. He claimed a dramatic improvement in his wife’s condition and that of other MS patients he treated.

News of Zamboni’s theory and treatment spread within the MS community via chatrooms and websites, leading hundreds of people around the world to seek the treatment, known as venoplasty (similar to angioplasty, in which a balloon is inserted into a blood vessel and inflated to remove a blockage).

In June last year I was interviewed by The Daily Telegraph about my battle – and failure – to obtain a diagnosis of, and treatment (if required) for, CCSVI in Britain and my decision to seek help abroad. Neurologists at my local hospital, the John Radcliffe in Oxford, claimed that it was not ethical or prudent to even attempt to diagnose CCSVI because of doubts about Zamboni’s work. Quite why it wasn’t “ethical” to use a safe, non-invasive diagnostic procedure (colour Doppler sonography) – which I was willing to pay for – to look at my veins continues to baffle me.

So I took my quest for venoplasty to a clinic in Athens which had treated many MS patients for CCSVI. You are reading the update on the treatment and my condition that readers were promised in that article.

I was the 45th MS patient to be seen by Constantinos “Costas” Kartkaletsis, a consultant vascular surgeon. After an initial examination, blood tests and a chest X-ray, he explained that a catheter would be inserted into the femoral vein in my groin and guided into my main trunk and neck veins. I was injected with anti-coagulant and put on a drip. I would have a local anaesthetic only and be fully conscious for the whole procedure.

I could feel the balloon inflating inside my veins but there was no pain. Restrictions were diagnosed in four major veins (the azygos vein, hemi-azygos, and the left and right internal jugular veins) in the trunk and neck, and all were treated using balloon venoplasty over three hours.

I had not expected any immediate impact, but Natasha’s surprise at the improved condition of my feet next morning left me elated. I could not explain what had happened but something had changed. Mr Kartkaletsis was interested in Natasha’s observation but he has a policy of treating restricted veins rather than commenting on any change in MS symptoms following treatment.

Back home, I planned complete relaxation for two months. I decided not to try to record frequent changes but to note trends on a monthly basis, as MS symptoms can vary daily.

At the end of the first month I felt my concentration had improved. People with MS use the term "cog fog" to describe the deterioration in cognitive functioning. Friends noticed that I no longer needed regular naps and that I focused better on conversations. After three months, I felt I was functioning mentally at least as well as I was a decade ago.

There were other changes, too: I'd had neuropathic pain (caused by damage to the nervous system) in my right leg for many years. That went and has not returned. After years of not recalling my dreams – an observation reported by many with long-term MS – I have, for the past six months, remembered them again. My need to get up at night to urinate also improved slightly, from three to six times to one to three times a night – something much appreciated by my wife.

My walking and balance have not changed over the past six months, and I still rely on my Musmate walking aid and trekking poles to get about. But, on the plus side, my osteopath David Harsant, at Oxfordshire's Multiple Sclerosis Therapy Centre, who made extensive notes before and since the procedure, reports gradual improvement in muscle tone, stiffness and spasm in my neck and back. He says my neck muscles felt "matted, congested and were indistinguishable." but after the venoplasty "the matted sensation reduced and the palpability of individual muscles increased".

Professor Zamboni has reported that some patients may require repeat treatments if their veins "re-stenose" after venoplasty. Vascular specialists are defining the best way to diagnose restricted veins, the veins to check, the best size, position, pressure and duration of ballooning. I expect to undergo another procedure when the method is finalised.

CCSVI remains a controversial diagnosis, as does its treatment. However, MS patients are at the forefront of spreading the word and the internet is making that easier. I have watched a doctor from Kuwait present his work on CCSVI to vascular specialists in New York, and heard an interview with a research neurologist who has collated doctors' reports on CCSVI. Expert patients like me are frustrated by the refusal of the MS establishment in Britain – neurologists and the MS Society – to accept the existence of this condition and consider testing for it. Since I went to Athens, testing for CCSVI and balloon venoplasty has become available to private patients at a clinic in Glasgow. The package costs £7,990 and there is already a waiting list.

Would I recommend the treatment to other MS patients? I would certainly encourage those with progressive MS to think about balloon venoplasty. There is a small risk of vein injury but, based on doctors' web reports on 2,000 people treated, I believe there is a chance that it may slow or halt progression of the disease. I was lucky that the cost of private treatment was not prohibitive but sadly this is not the case for many. I have tried explaining to neurologists and vascular doctors why CCSVI syndrome should at least be considered as a possibility in patients with MS but to no avail. Only my caring, supportive GP was prepared to listen. Medical journals refuse to publish patients' point of view – I know because I've tried that, too. One has to ask what the neurology establishment is so frightened of: opening the veins of those with MS or opening their own minds.

The Essential Health Clinic www.essentialhealthclinic.com

MS and CCSVI syndrome

Multiple sclerosis (MS) is a degenerative disease of the nervous system affecting 100,000 people, most of them young adults, in the UK. It is believed to be autoimmune in origin, (meaning the immune system mistakenly attacks the body's own cells) and triggered by genetic or environmental factors, or a combination of both. These cause immune cells to cross the blood/brain barrier (which keeps blood and cerebrospinal fluid separate) and

attack the fatty, white myelin sheath that surrounds and insulates nerves in the brain and spinal cord.

The symptoms of MS vary widely, as does the severity of the disease. In some people, it progresses relentlessly. Other patients suffer the relapsing and remitting form – periods of relative good health interspersed with flare-ups and neurological deterioration. Several treatments are available of varying efficacy, including immuno-modulator drugs (which, as the name suggests, inhibit the immune system) and steroids.

Research by Professor Paolo Zamboni, director of the Centre for Vascular Diseases at the University of Ferrara in Italy, has led him to call for a radical rethink on MS. He suggests that MS is not only an autoimmune disease, but also a vascular one, caused by restricted, blocked, malformed or twisted veins in the trunk and neck. A small study showed that 90 per cent of his patients with MS had venous obstruction. Prof Zamboni has named the condition chronic cerebrospinal venous insufficiency (CCSVI) syndrome. It is characterised by stenoses (narrowing) of the internal jugular vein (which runs down the side of the neck) and/or the azygous veins (which run up the side of the vertebrae). These veins drain blood from the brain and the spine into the heart.

Prof Zamboni said that two pilot studies demonstrated the safety and feasibility of day surgery for treating CCSVI by means of balloon angioplasty, also called balloon venoplasty, using minimally invasive techniques to unblock the obstruction. As yet, only initial pilot studies have been published as to the effectiveness of this experimental treatment.

He also suggests that an excess of iron, which causes inflammation and cell death, was responsible for tipping the immune system out of balance, resulting in MS symptoms.

British neurologists and the Multiple Sclerosis Society are extremely sceptical of Prof Zamboni's work, stating that MS patients should wait until ongoing research into his claims is completed before embarking on treatment.

More information from www.CCSVI.org