



**A U S T R A L I A**  
Giving life back

# CCSVI

## Your questions answered

---

**There has been a lot of media attention and general interest surrounding CCSVI as a possible cause of multiple sclerosis (MS). This information sheet helps answers some commonly-asked questions about CCSVI, its treatment and what this all means for people living with MS.**

---

### What is CCSVI?

CCSVI stands for 'chronic cerebrospinal venous insufficiency'. It describes a situation where there is reduced blood flow from the brain and spinal cord over a prolonged period of time.

---

### Why is CCSVI relevant to MS?

The concepts surrounding CCSVI and MS are based on a small study conducted in 2009 by Italian doctor Paolo Zamboni and his team. Using ultrasound technology, the researchers examined cerebral venous drainage (blood flow from the brain and spinal cord) in 65 people with MS, compared with 235 people who were healthy or who had other neurological disorders.

The results showed a strong correlation between having MS and signs of venous insufficiency (reduced blood flow). Professor Zamboni and his team called this 'chronic cerebrospinal venous insufficiency' (CCSVI). The team suggested that the reduced blood flow from the brain and spinal cord may trigger the inflammation that is known to cause damage in the central nervous system of people with MS.

A further study from the same group looked at the effects of draining the excess blood from the brain. As part of the study, the 65 people with MS (who had all presented with 'blockages' in the initial study) underwent angioplasty – an invasive technique that widens obstructed or narrow blood vessels using a small balloon at the end of a catheter. Following the surgery, the group reported some positive results, including a reduction in new lesions; however, in 47 per cent of participants, the jugular veins (veins that bring blood back from the head to the heart) returned to having restricted blood flow.

Similar research is also underway internationally. For example, in February 2010, the University of Buffalo Medical Center in New York issued a press release describing preliminary results from an ongoing study led by Dr Robert Zivadinov into the prevalence of venous obstruction in people with MS. Doctor Zivadinov presented data on the first 500 participants in this study, 289 of whom had MS. Results were less dramatic, with ultrasounds revealing blockages in 62 per cent of people with MS, 26 per cent of healthy participants, and 45 per cent of people with other neurological disorders.

Another group of researchers, Doepp et al (2010), evaluated cerebral venous system function and also tested the CCSVI and MS theory. The researchers studied 56 people with MS and 20 control individuals using ultrasound to characterise cerebral veins. The study found no difference between people with MS and control individuals with regard to blood flow. Moreover, no abnormal changes were noted in the MS group in jugular vein blood flow. From their findings, Doepp et al concluded that there was no indication of blood flow congestion in people with MS.

So, while the early data is interesting, the theory is considered to be highly speculative. The main limitations are that studies have been done with relatively small numbers of people and on those who already have clinical MS. It is, therefore, difficult to distinguish whether the venous obstructions are the cause of MS or are part of the physiological changes in the central nervous venous system resulting from MS.

More information is needed to understand the full implications of the research to date. Diagnostic testing of the cerebral venous system is imprecise and the use of ultrasound to measure venous physiology hasn't been validated. Chance, bias from various sources, design flaws, lack of objectivity, or a combination of these factors might also have influenced the results of one or all of these studies.

There are also well documented patterns among people with MS that do not appear to fit the theory that CCSVI is the primary cause of MS. These include the reduction of inflammatory activity in people over 50 or the geographic distribution of MS. If it is to be scientifically established that CCSVI causes MS, these and other well documented factors need to be explained in a way that is consistent with Professor Zamboni's theory.

In an international call for research proposals, the US and Canadian MS Societies have committed \$2.4 million (US dollars) to fund seven CCSVI research projects. Commencing in June 2010 and running for two years, most of these studies will explore whether venous obstruction is more prevalent in people living with MS than in the general population. Rigorous research protocols have been established and patient screening has begun.

---

## Can treatment for CCSVI cure MS?

The research to date has had many limitations and is not yet complete. The concepts surrounding CCSVI (including the effectiveness of treatments) are still relatively new and need to be validated by large-scale clinical trials before they can be established.

To date, two treatments have been used for people with MS who have been found to have CCSVI. The first was catheterisation of the blocked veins (the insertion of a small tube to open the vein, as used in Professor Zamboni's study) and more recently by stenting the blocked veins (the insertion of a small valve into the blocked area of the vein).

While both of these surgical techniques are commonly used in heart surgery, the effectiveness and level of benefit versus the risk is yet to be established for treating MS. Although the people treated by Professor Zamboni's team did experience some improvement in their MS, there are a number of factors that may be involved.

It is known that in almost half of the people treated, the blockage re-formed. We also only know the effects after 18 months of participants having the treatment. The long-term effects are not known.

---

## If the treatment for CCSVI cannot cure MS, can it treat MS?

Treating CCSVI may lead to improvements for people with MS, but the information to date does not prove this. The study reported by Professor Zamboni and his team only included 65 people with MS. While it is documented that on average the group treated for CCSVI experienced improvement in physical and psychological measures of their health, the treatment was more effective for the people with relapsing-remitting MS.

It is also worth noting that people with relapsing-remitting MS who were treated for CCSVI continued to take their immunotherapy medications, which are well documented as producing the types of improvement seen in this study. Before it can be established that treatment for CCSVI is also an effective treatment for MS, there needs to be more extensive research demonstrating significant and consistent results.

## If there is a chance that treatment for CCSVI could help, why not give it a try?

In addition to knowing whether a treatment is effective, it is also important to know whether it is safe. There are several uncommon but potentially fatal outcomes from inserting stents into veins. The risk of serious negative outcomes does not necessarily mean that treatment should not be considered, but it is essential that the decision is looked at more carefully.

In order to make an informed decision about treating CCSVI to improve MS, it is recommended that treatment should not be considered until properly conducted clinical trials have established the need. Decisions about any treatment should be made in careful consultation with the person's treating specialists and healthcare team.

---

## What is MS Australia's position on CCSVI?

With a complex disease like MS, it is important to consider all possibilities when searching for causes and treatments. Professor Zamboni's theory about CCSVI and MS is taking a new approach to MS research. While existing data suggests that there may be a relationship between CCSVI and MS, so far there is insufficient information to understand what the relationship is, or what it means for treating MS.

MS Australia, through its research arm MS Research Australia (MSRA), is contributing to the worldwide effort to gather this information. MSRA is funding a CCSVI study at the Austin Hospital in Melbourne to identify and measure the frequency of narrowed veins in people with MS and controls.

MSRA is also communicating with MS societies around the world to keep abreast of current research and inform the Australian MS community of advances made in this area. MS Australia supports new treatments which may improve outcomes for people living with MS, but can only do so after those treatments have been subjected to rigorous scientific testing and review.

Based on current evidence and the potential dangers of being treated for CCSVI, MS Australia does not recommend that people with MS seek surgical treatment for CCSVI outside of controlled clinical trials. Individual decisions about any treatment for MS, taking into consideration potential benefits, risks and side effects, should be made in careful consultation with your treating specialist.

---

## If CCSVI treatment is being considered, it is important to note:

- There have been documented complications with the use of stents. MS Australia does not recommend the use of stents during CCSVI therapy for MS.
  - Receiving CCSVI therapy as part of a controlled trial is supported if it will contribute to the research being conducted into the treatment of MS.
  - People living with MS should communicate with their doctor, neurologist and family members before deciding to undergo CCSVI therapy.
  - If the person with MS and their specialist decide that CCSVI treatment is appropriate, it is recommended that procedures be performed in Australian hospitals where ongoing care can be provided.
-

## Further information on CCSVI research and other treatments for MS

- **Speak to your neurologist** or other treating specialist about the implications of CCSVI and what treatment best suits your individual circumstances.
  - **MS Australia** provides information on treatments currently available in MS: [www.msaustralia.org.au](http://www.msaustralia.org.au)
  - **MS Research Australia (MSRA)** provides information on the latest research and clinical trials in MS: [www.msra.org.au](http://www.msra.org.au)
  - **For all media enquiries**, please call Jenny Crocker on 0437 139 078.
- 

## Bibliography

- Ascheiro A, Munger KL. Environmental risk factors for multiple sclerosis. Part I: The role of infection. *Ann Neurol* 2007; 61:504-13.
  - Ascheiro A, Munger KL. Environmental risk factors for multiple sclerosis. Part II: Noninfectious factors. *Ann Neurol* 2007; 61:504-13.
  - Doepp F, Paul F, Valdueza J, Schmierer K, Schreiber SJ. No cerebro-cervical venous congestion in patients with multiple sclerosis. *Ann Neurol* 2010; 68(2):173-83.
  - Doepp F, et al. How does the blood leave the brain? A systematic ultrasound analysis of cerebral venous drainage patterns. *Neuroradiology* 2004; 46:565-570.
  - Khan O, Filippi M, Freedman MS, Barkhof F, Dore-Duffy P, Lassmann H, Trapp B, Bar-Or A, Zak I, Siegel MJ, Lisak R. Chronic cerebrospinal insufficiency and multiple sclerosis. *Ann Neurol* 2010; 67(3):286-90.
  - Multiple Sclerosis Research Australia (MSRA). Update on CCSVI and MS. Sydney: MSRA, December 2009.
  - Samson, K. Experimental multiple sclerosis vascular shunting procedure halted at Stanford. *Ann Neurol* 2010; 67(1):A13-5.
  - Singh AV, Zamboni P. Anomalous venous blood flow and iron deposition in multiple sclerosis. *J Cereb Blood Flow Metab* 2009; 29:1867-78.
  - University of Buffalo. First blinded study of venous insufficiency prevalence in MS shows promising results. News release. Buffalo: University of Buffalo, February 2010.
  - Zamboni P, Galeotti R, Menegatti E, Malagoni AM, Tacconi G, Dall'Ara S, Bartolomei I, Salvi F. Chronic cerebrospinal venous insufficiency in patients with multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2009; 80:392-9.
  - Zamboni P, Galeotti R, Menegatti E, Malagoni AM, Gianesini S, Bartolomei I, Mascoli F, Salvi F. A prospective open-label study of endovascular treatment of chronic cerebrospinal venous haemodynamics in the assessment of multiple sclerosis. *J Vasc Surg* 2009; 50:1348-58.
  - Zamboni P, Menegatti E, Galeotti R, et al. The value of cerebral venous haemodynamics in the assessment of multiple sclerosis. *J Neurol Sci* 2009; 282:21-7
- 

## For information about MS and MS Australia services:

**Free call™: 1800 042 138**

**Web: [www.msaustralia.org.au](http://www.msaustralia.org.au)**

---

**Disclaimer:** Information contained in this fact sheet, prepared by Multiple Sclerosis Limited (MSL), is intended to provide useful and accurate information of a general nature for the reader but is not intended to be a substitute for legal or medical advice. MSL is not recommending medical or legal advice and readers must seek their own medical or legal advice as may be appropriate. Printing and photocopying this publication in its original form is permitted for educational purposes only. Reproduction in any other form without the written permission of MSL is prohibited.

---