World Multiple Sclerosis Day

SPEECH
Monday, 30 May 2011

BY AUTHORITY OF THE HOUSE OF REPRESENTATIVES
Ms SAFFIN (Page) (19:10): I would like to thank the honourable member for Chisholm for affording us the opportunity to talk about MS tonight, particularly as World Multiple Sclerosis Day was on 26 May. I want to talk about two things. Firstly, in my area there is a local group, the Australian Multiple Sclerosis Network of Care, whose members are very active in providing support to each other and in advocacy to the medical profession and to me. The group has been promoting chronic cerebrospinal venous insufficiency, CCSVI. I will talk a bit about that and then about MS Australia and the good work that they do.

Peter Sullivan, the coordinator of the Multiple Sclerosis Network of Care, has prepared a discussion draft entitled *CCSVI in Australia—a strategic overview—from the perspective of those with MS*, dated May 2011. It is really well written and it sets out what the issues are. I cannot pretend to understand all the medical issues, but I can see that a group of people who are suffering from MS are saying, ‘We benefit from this particular treatment in this particular area,’ and there are some issues of contestability around that, which there often are in terms of making advances in medical treatments.

Peter Sullivan has said that he would like to see formal recognition of CCSVI as a vascular disorder in its own right. He would like to see participation in the introduction of programs to bring the medical profession up to speed. But I have to say that often the medical profession have to bring us up to speed; it is not just one leading the other. Peter Sullivan calls for funding programs to monitor the long-term effectiveness of treatment procedures, including but not restricted to clinical trials recommended by vascular specialists. He would like to see funding and promotion of a national CCSVI screening program. Currently, 25,000 people are involved in screening. In some situations Medicare rebates are available, but it is a confused area. He believes that there should be assistance for those without private insurance to gain access to appropriate treatment and care. I am not sure what the implications of those requests would be, but Peter asked me to put that forward and I said that I would be happy to do so as a representative and advocate. I note that the MS Australia website has a page on CCSVI headed ‘Your questions answered’ and that there are differences between what MS Australia says and what the MS Network of Care says. But this is certainly an emerging issue that we will have to turn our minds to.

The second matter I wish to raise is that the honourable member for New England wanted to speak in this debate tonight, particularly as this issue relates to health, but he is occupied elsewhere. Our electorates of Page and New England share a border. I know that the honourable member particularly wanted to put on record some comments and research provided by Robert Pask and Alan Blackwood from MS Australia. Figures provided by them show that around 10 per cent of the workforce is lost to chronic disease. Eighty per cent of people lose jobs in the first 10 years after being diagnosed. Eighty-seven per cent of people with MS are of working age. Early intervention may help keep people in the workforce and, presumably, keep some off the DSP. People eligible for DSP can now work up to 30 hours before being penalised. The previous threshold was 15 hours, and that is a welcome change. Fifty-eight per cent of carers of people with MS report having to change their work hours—that is a big loss—and 540,000 full-time workers are lost to our economy each year due to chronic disease.