

Jane Houghton Recounts Her Presentation with Dr. R. Tusa,
June 27, 2006
Southampton, England

What I am about to write is a combination of what I remember and hubby Neil's contribution (and notes that he made during the presentation). Please feel free to use/post any part of it to the support site, future newsletters, Maldebarq etc, alter it as you see fit, and feel free to ask me any questions. Whatever I write is not meant to offend, upset etc, I am merely trying to recall what was said by Dr Tusa So please do not let anyone on the support site shoot the messenger!

Tusa ran two consecutive lectures each lasting about fifty minutes. Never before have, I heard the subject discussed for so long, with such accuracy! Sixty-five delegates from around Europe attended the three-day Conference, of which about 37 chose the MdDS workshops. One of the first questions he asked was who in the room already knew about MdDS, about 17 (the total of both workshops) said they had either heard of it or come across cases themselves. All of the sixty-five attending received a brochure in their Course Welcome Pack, which I had sent in advance to the organiser. She also took a further fifty from me just before we left.

He began by saying that although he is on the medical advisory board for the American MdDS Foundation he isn't on our payroll, and includes the condition in his talks because he wants to raise awareness and share his experiences in treating, diagnosing etc with others from the medical profession. Throughout the talk, he spoke very highly of our Foundation, and you will be very pleased to know did in fact use the slides that Linda had compiled, each time acknowledging that they were from the Foundation. He was very complimentary about the newsletter as well, emphasising to his audience how pro-active we are, and that certain members (Roger) aren't averse to occasionally giving the Medical Advisory Board a hard time!

Now regards diagnosing MdDS he said he personally uses three criteria. Firstly, it has to be "passive motion induced" – secondly it has to have lasted for at least 30 days, and thirdly symptoms should be relieved when back in motion.

Spontaneous MdDS or MdDS that has been triggered post-operatively, or as a result of an infection, he terms as "pseudo MdDS" – although not motion

triggered he stressed that the other two criteria are still applicable (at least 30 day duration and relieved by being back in motion), his approach to the treatment of both is the same.

He told the audience that no test reveals MdDS, but he did stress the need for the patient to be seen as quickly as possible after onset for any kind of treatment to be effective. In fact he classed it as an “emergency” referral and would attempt to see a patient within a week. He believes if a MdDS patient isn’t treated within a year of onset then, in his words, the outlook is “poor”.

So to treatment – he encourages the patient to be as active as possible, and recommends regular exercise of the patient’s choice. He doesn’t actually provide them with an exercise programme as such, but stated that patients should avoid exercise that creates sensory mismatch, his example being the treadmill, definitely a no-no!

Regards medication he recommended the following approach, to begin with a low dosage SSRI, but not used in its capacity as an anti-depressant. If there are no side effects from that, he keeps them on this for 30 days, after which he sees them again and then if there is no improvement in their symptoms he adds 0.25mg of Klonopin. This approach he found most beneficial if once again the patient was seen in early onset.

He talked about anxiety being a problem with this condition and “personality” types but you will be relieved to hear Roger that he stresses that it is not compulsive/obsessive/perfectionists that are more prone to MdDS but rather they are the ones who find it harder to live/cope/accept/habituate to this condition.

Right, others points he touched on, in no particular order are, he doesn’t think this is gender specific, rather as we know, he feels women tend to seek out more answers to their health problems than men. Also, his recommendation should a patient go into remission, is to avoid the previous “trigger activity” if possible. Long car journeys should be broken up with regular ten-minute stops where the sufferer should get out of the car and walk around. He feels that the condition is more likely to be a CNS problem, than an inner ear one. We both shared our concern that MdDS shouldn’t become what he termed the “waste paper basket” for all vestibular orphan disorders without a “label” – he truly believes that it is a specific defined condition. Also, someone in the audience quoted that MdDS is a

"self-limiting" condition, but Tusa disagreed saying that not getting your land legs back is what is termed a self-limiting condition, this isn't true of MdDS.

Once he had covered these areas then he handed over the floor to me, giving me "centre stage" if you will (quite brave of him actually seeing as he had never met me before!) He wanted me to tell my whole story from the beginning..... How I got MdDS, how I found out about it, any effective treatments so far, the impact it has had on my life..... you know the whole works. After which the delegates were able to ask me questions about any aspect. These ranged from the usual ones - was I a good traveller pre-MdDS? To ones such as, had any sufferer that I knew ever tried cognitive therapy as a treatment?

I explained at the start (rather like my disclaimer to them) that everything I was about to say was from a patients perspective, not a medical one, so I was sorry if they took exception to anything. The interaction was good....again it was only my opinion, but I said that I now believed that I had this condition for life (which was met by some gasps from the audience, which I thought was touching) but I noted with interest that Tusa nodded in agreement to my statement!

I talked about it being hard to convince people, medical and otherwise, about having this invisible condition, thus adding to the isolation and suffering already felt by those affected. Although I did say that I could understand peoples reluctance to accept MdDS given the fact that I look "normal" and as I said to the group I could be sat here today making the whole thing up, especially as nothing shows up in testing as well! Straight away Tusa interrupted me and said... "But she's not; MdDS is a very real, genuine condition!" I was so impressed by his defence and passion to make them understand the seriousness of it all, and the challenges that we face, not just at that point in proceedings, but throughout the whole workshop.

To conclude I found the whole experience extremely valuable, and that's with my serious nerves before we got started! Without doubt, well worth the four-hour drive, it took us to get there (and that's with little traffic on the roads and Neil's manic driving!) After meeting Tusa I believe we are very fortunate to have him on our Advisory Board, and I discussed with the event organiser the possibility of attending future events, not least the "Tusa Tour 2008!"