

Mal de Debarquement Support News

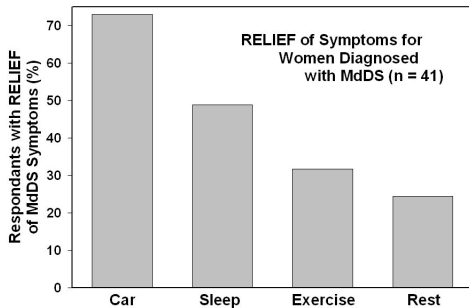
A Newsletter for the International Members of the MdDS Support Group and the Professionals Who Treat Them

Volume 14

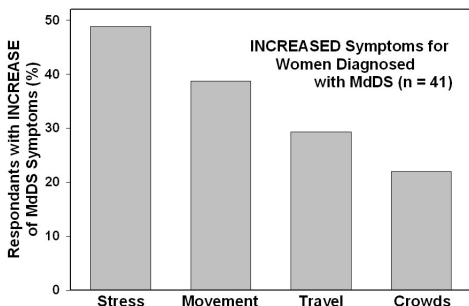
March, 2007

MdDS Symptoms: Cause and Relief

Almost everyone with MdDS experiences temporary, intermittent relief of symptoms. Results from one of our [online databases](#) have provided an indication of the most often described circumstances that reduce symptoms. Among females diagnosed with MdDS, 30 of 41 (73%) noted a reduced awareness of MdDS while moving in an automobile (see Fig below); perhaps this simply reflects alignment of brain-perceived movement with actual movement. Sleep, exercise and rest also provided relief.



Unfortunately, most with MdDS also experience an increase in symptoms in association with diverse routine activities; these were less consistent among this same group of women. Thus, responses by a given individual are more variable. Stress was the most common event associated with increased symptoms (see Fig below). Other activities also increased symptoms, *i.e.*, movement, travel, and crowds.



Based on the above, it is clear that many aspects of daily living exacerbate MdDS symptoms. Hopefully, additional information about symptom relief and cause from future studies will point to an anatomical or physiological basis for this disorder.

Waiting for My Ship to Dock

February 13, 2007, marked one year that I have been on this "ship at sea", so I felt it would be appropriate to share my story. My husband and I went on a four night cruise from Galveston to Cozumel. We were first time cruisers and looking forward to a relaxing vacation. The cruise was a rough ride from start to finish but for about 24 hours we experienced 40 mph winds and 15 foot waves. We both wore the Transderm patch. Upon our return home, I did not feel well so I went straight to bed. As I lay in bed, I felt like I was still on the cruise ship rocking to and fro. I thought that one morning I would wake up and this feeling would be gone. Over the next few weeks, I went to my family doctor, an ENT, and a neurologist. I had blood work, urinalysis, hearing and ear pressure tests, and a MRI of my brain which all returned normal results. The ENT originally diagnosed me with Vestibular Neuritis but threw his hands up after seeing normal test results. He then referred me to a neurologist who prescribed Antivert.

Meanwhile, I was trying to work at my job on the 27th floor of a 30 story building which meant taking an express elevator up and down. I missed many days of work because if I worked one day, I was so wiped out I could not work the following day. Also, when I was on the 27th floor, I could literally feel the floor moving under my feet and could hardly walk down the hallways. This caused me to be nauseous most of the time. I had to hold on to the wall to steady my balance and keep from falling. My job also required attention to detail, heavy concentration, and the ability to multi-task. These skills became impossible with the constant motion in my head 24/7 and the fatigue that accompanied it. Eventually, I was put on medical leave.

In April I decided to try on my own to find a doctor who could help me. I searched the internet and found a neurologist. Prior to seeing him, I went through balance and audiology tests. The neurologist reviewed the test results along with the MRI and lab work and immediately diagnosed me with MdDS. He gave me some exercises to do five times a day and told me to come back in a month if I had not improved.

In May, my symptoms spiked to higher levels, and I had to hold on to the walls and furniture to walk around my house. Shortly after this, I started trying to walk outside every morning. I felt better outside than inside but felt bouncy in my head when walking. I eventually worked up to walking one mile every morning and continue to walk at least a mile each morning.

I continued to see the neurologist on a monthly basis and each time we had to change my medication. I tried several medications at different times including Zofran, Valium, and Klonopin.

I saw an acupuncturist several times with no change in symptoms, so I discontinued treatment. In August, the neurologist began treating me with Amitriptyline. In September, I began seeing some improvement with my balance. Also, things that bothered me in the beginning of my MdDS like walking in the mall or grocery store improved. I am lucky to have a supportive husband and the support of the wonderful people in the MdDS Yahoo! Support Group. This support has helped me tremendously to deal with this horrible disorder. I am really hopeful that this ship I am on will dock soon, and I can return to the quality of life I had prior to the cruise. Female, 44 year old

Foundation Finances

There were three Matching Donation Challenges in place between January 18, 2007 and February 22, 2007. Thank you to those who initiated the challenges and to those who helped us meet the goals including our constant contributors and a number of new ones.

Matching Donation Challenges:		
Challenge	Donations	Total
\$1000	\$1016	\$2,016
751	770	1,521
900	973	1,873
Grand Total		\$5,410

We also had \$2,850 donated after the challenges were complete which means in the last month we have received a total of **\$8,260** to apply to Foundation goals.

Please send tax deductible contributions to:

MdDS Balance Disorder Foundation
Marilyn or Roger Josselyn
255 Copper Beech Drive,
Blue Bell, PA 19422
<http://mddsfoundation.org>

One of our main goals is to identify a researcher to study a cause and a cure for this life altering and often debilitating syndrome. Please contact the editor if you can help us with this endeavor.

For health care, MdDS is Indexed: ICD-9 780.4

If you are interested in volunteering to assist with our programs, please email:

Roger at rjosselyn2@comcast.net or
Marla at mcrnor@msn.com
mddsfoundation@yahoo.com

Send comments, questions, or suggestions to the Newsletter Editor (editor@mddsfoundation.org)

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