http://www.dizziness-and-balance.com/disorders/central/mdd.html

Mal de Debarquement Syndrome (MDD or MdDS)

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Mal de Debarquement or "MDD" is a type of vertigo and imbalance that occurs after getting off of a boat. The usual situation is that of a person who has gone on a cruise. We use the abbreviation "MDD" here for clarity, because it has been used in the past. It has been pointed out that "MDD" can be confused with other disorders, and some prefer to use "MdDs" or various combinations of these letters.

To our knowledge, the first reference to the syndrome was made by Erasmus Darwin, in 1796. He wrote:

"Those, who have been upon the water in a boat or ship so long, that they have acquired the necessary habits of motion upon that unstable element, at their return on land frequently think in their reveries, or between sleeping and waking, that they observe the room, they sit in, or some of its furniture, to librate like the motion of the vessel. This I have experienced myself, and have been told, that after long voyages, it is some time before these ideas entirely vanish. The same is observable in a less degree after having travelled some days in a stage coach, and particularly when we lie down in bed, and compose ourselves to sleep; in this case it is observable, that the rattling noise of the coach, as well as the undulatory motion, haunts us. " (Darwin, 1796).

Most individuals with this diagnosis are women between the ages of 40 and 50 who go on a 7-day cruise. After getting off the boat, or "debarking" (debarquement), they develop a rocking sensation, as if they are still on the boat. The rocking sensation may persist for months or even years ! Most people seem to have it for a month or less though -- our study largely recruited people with longer duration symptoms, 3.5 years was the mean (Hain et al, 1999)



What Causes Mal de Debarquement?

Little is known about this rare disorder. It is the general opinion, however, that MDD is **not** caused by an injury to the ear or brain. At this writing (8/2007), the predominant opinion is that MDD is a variant motion sickness. MDD is associated with postural instability after sailing (Nachum et a, 2004). While this theory doesn't explain why MDD seems to mainly affect women in their 40's it does seem to account for observations of naval personnel who have a similar land-sickness experience.

Some dizziness experts believe that MDD is caused by a variant of <u>migraine</u>. Others think that it is caused by inappropriately high weighting of somatosensory input for balance (Naichem et al, 2004). As somatosensory information and vestibular unreliable on a boat, this is a difficult explanation to follow. We think that the internal model theory explanation (which follows) is the better one at this writing (2007). A recent conjecture is that MDD is caused by adaptation to roll while rotating. In other words, if one is rocking side-side (roll), and also rotating the head, for long periods of time, one might develop an inappropriate cross-coupling between roll and rotation (Dai et al, 2009). Our position on this idea is that it could explain brief (2 hour) symptoms after getting off of a boat, and also offers an explicit hypothesis that might be tested formally (i.e. people who do a lot of head rotation on a boat would be more likely to get this than people who sit quietly).

Because the condition largely occurs in females, it may also have something to do with sex hormones, such as estrogen or progesterone. It could also be genetic, related to two copies of the 'X' chromosome perhaps combined with other susceptibility factors. The "Norwalk" virus is common on cruise ships, and perhaps this syndrome is somehow related to this virus. It seems unlikely to be a psychological disturbance -- although it is always difficult to entirely exclude psychological problems, the male:female ratio and other aspects of this disorder would make this unlikely.

Moeller and Lempert (2007) recently suggested that MDD is due to "deafferentation" or panic. We disagree with both of these ideas.

Note that the MDD of "Mal de Debarquement" has nothing to do with the other MDD of "Manic Depressive Disorder". The support group for MDD, being sensitive to this, has suggested that the proper name of the syndrome would best be "MdDs". Our own feeling is that there are many medical disorders that share initials with other disorders (PAN is an example -- periodic alcohol nystagmus and periodic alternating nystagmus), and we prefer the simplicity of MDD.

Internal model theory and MDD

A plausible mechanism for the development of MDD is that it is due to formation of an *inappropriate internal predictive model*. Internal models are sophisticated estimators that have been used to explain such difficult observations that one cannot "tickle" onself (see the work of Wolpert and others). Examples of internal models are very easy to find in daily life -- suppose you pick up a suitcase, expecting it to be full, but it is empty !. Internal models are sophisticated methods of reacting to events even before they happen !

On a boat, one is faced with a difficult balancing problem, with components of rotation (pitch plane rotation -- about the axis between the ears), and linear movement (surge -- front-back movement of the boat). Both are somewhat predictable as the boat is large and it's interface between it and the ocean constrains it to low frequencies of movement.

Lets take an example -- when the boat pitches forward, there is a small amount of pushing the person backward accompanied by a tilt of the visual world as the angle between upright and the boat surface becomes more acute. To stay upright, a person should not activate their ankle muscles much as inertia tends to keep their body upright. Oh the other hand, when the boat surges backward and there is an accompanying tilt forward of the body due to inertia causing a similar backwards torque on the ankles and change in visual angle, a person should react vigorously and stiffen their ankles-- because their center of gravity is no longer over their ankles -- and a fall may occur. Thus the same general proprioceptive cue on the feet as well as visual stimuli needs to trigger opposite responses -- loose ankles or stiff, depending on the context.

How does the brain figure out the context with the same visual stimuli ? In both cases, body inertia keeps the vestibular system fairly close to upright. We propose that people develop a predictive model of the boat motion, and use their prediction to adjust to the boat motion (and avoid falling).

Normally, it seems likely that over a few days, people develop an internal model of periodic motion on the boat so that they predict and cancel out input (visual or somatosensory) that is phase-locked to pitch rotation, and enhance visual input due to surge that is not. The internal model normally is disposed of once the person returns to terra firma, again over a period of

hours to days. Persons with MDD are unable to dispose of this internal model, which is only useful when they are exposed to periodic motion (such as when driving a car).

This theory explains most of the features of MDD, and would also suggest that treatment approachs should be considered that assist people in changing their mental processing of motion, rather than searches for vestibular suppressant medication or physical therapy that includes more motion.



The diagnosis is made by a combination of the history (rocking after prolonged exposure to a boat), and exclusion of reasonable alternatives. Tests to exclude <u>Menieres disease</u> should be done, and if there is a history of plane flight, <u>perilymph fistula</u> should also be considered. A typical patient is a woman of appropriate age (see figure to the side), who has gone on a cruise and who is now rocking.

In my practice, I get the following tests:

- <u>Audiogram (expect normal, abnormal suggests other disorders)</u>
- <u>VEMP</u> (an evoked potential test looking for saccule disorders, also generally normal)
- Blood tests for <u>autoimmune disorders involving the ear</u> (ANA, anti-microsomal antibodies)
- <u>Video-ENG</u>. This is the most arduous and least useful of the MDD studies. The result is usually normal, but occasionally may find unusually strong or prolonged optokinetic or vestibular responses, and there is also sometimes direction-changing positional nystagmus as has been reported by Brown and Baloh in 1987
- <u>Rotatory chair test.</u> This is not quite as difficult as the ENG, and usually shows very strong vestibular responses.

Treatment for Mal de Debarquement

After MDD has started, most medications that work for other forms of dizziness or motion sickness are ineffective. Specifically, antivert (bonine, meclizine), dramamine, and scopolamine seem to be of little use. The author has tried out many other medications, and has also not found response to more unusual agents for dizziness such as betahistine, baclofen, or verapamil.

- Low doses of **Klonapin**, a benzodiazepine medication related to Valium (diazepam), are helpful in most persons with MDD. There is some worry that these medications may prolong the duration of symptoms (although this worry has not yet been tested by a research study).
- We have also had recent success with treatment with venlafaxine -this is an antidepressant that is very useful in migraine. We use the same protocol as for treatment of migraine (top dose typically only 37.5 XL).
- Occasional patients have reported improvement from treatment with Neurontin (gabapentin)
- Occasionally persons with rocking due to other causes respond to one of the SSRI type antidepressants, and this may also be worth considering. **Paroxetine** is the most common SSRI used in persons with dizziness.
- We have been told that **non-steroidal anti-inflammatory** medications have helped, but this does not seem to be a general pattern.
- Also anecdotally, **phenytoin** and carbamazepine (or oxcarbazepine -- see above) may be useful in reducing symptoms. Phenytoin has been reported useful in motion-sickness. A controlled trial of these medications may be in order if more evidence accumulates.

Medications to stop and procedures to consider stopping.

- **Hormonal medications** such as estrogen or progesterone might be problematic -- it might be worth a trial of stopping them if this is practical.
- We are uncertain whether physical therapy is helpful in MDD.
- In our opinion, none of the following has any reasonable role in treating MDD
 - Acupuncture
 - \circ Chiropractic
 - Cranio-sacral therapy
 - Dangerous medications of any type
 - Herbal medications
 - Vitamins (such as lipoflavenoids)

Prevention of MDD

Medications taken prior and during boat travel might prevent development of MDD.

- According to Cha and others (2009), having migraine increases the probability of recurrent MDD. It would seem logical that medications that prevent migraine might also modulate MDD. *We are presently looking at this situation in patients taking venlafaxine.*
- Anecdotal evidence suggests that while antivert and scopolamine are ineffective, people can prevent MDD by taking very small amounts of Valium, Klonapin, or

Ativan (lorazepam) prior to getting on the boat or airplane. *The author has used this strategy in his patients many times with excellent results.* The usual dose is 0.5 mg, at start of trip and every 8 hours. For cruises, once every 12 hours is sufficient. Again, this strategy has not been tested by a research study and a trial, perhaps controlled with one of the medications known not to prevent MDD might be helpful. Nevertheless, medications which suppress the inner ear or block adaptation to inner ear signals might be useful.

• Some have suggested to us that exercises done prior to getting back on the boat might prevent MDD. Given our present theory of mechanism, we would find this idea very implausible. We do not know of any examples of this working or not working.

Physical Therapy for MDD

Physical therapy: <u>The evidence for a positive role for Physical Therapy in MDD is</u> <u>somewhere between nonexistent and weak (Hain and Helminski, 2007).</u> In our original study, 10/15 persons who had vestibular rehabilitation reported improvement, but the natural history of MDD is to improve, and one wonders what would have happened had they not undergone rehabilitation. In other words, this was an uncontrolled study, which sheds no light on whether PT is helpful. Zimbelman (1999) has written a review of rehabilitation in MDD.

While, we find this very doubtful, if MDD is indeed due to inappropriately high weighting of somatosensory input, <u>vestibular physical therapy protocols</u> that teach down-regulation of somatosensory input may be helpful. A controlled trial of vestibular rehabilitation in MDD would be helpful.

We have tried the "*Puma*" protocol exercises in a few (about 5) patients with MDD. None of them were able to perform the exercises, because it made their symptoms so much worse. Nevertheless, we are sympathetic to the general idea that things that make you feel worse (when you are dizzy) usually does result in some improvement (if you can stand it). The Puma protocol exercises are just so extremely stimulating that so far -- nobody has been able to tolerate them for more than a session or two. The Puma protocol exercises can be bought on the web in the form of a DVD from Dr. Puma's website.

Our suggestions for physical activity:

- Avoidance of periodic motion is probably helpful (Teitelbaum, 2002). If you get dizzy from riding on boats, don't do it !
- We also tentatively think that large amounts of driving would be a bad idea. Internal model theory would suggest that it would be better to be a passenger than a driver (to prevent MDD), but again, this is not established.

Going on another boat:

- Well -- if you must, we advise taking small amounts of klonapin during the cruise (see "prevention" above).
- Situations where there is a direct confrontation between the rocking sensation of MDD and a very clear and normal sensorium seem reasonable. In other words,

walking outside (on a calm day), on a firm surface, where you can see the horizon, might be helpful.

• Doing things that makes the symptoms better (such as driving a car for long periods), might (in theory anyway) prolong the duration of MDD.

Research is needed

MDD is not very well studied. Only 20 papers come up on a "Pubmed" search. Considering that many other obscure conditions have 1000's of papers written about them, this means that MDD has been generally ignored. There are many open questions. Here are a few:

- Controlled trial of medication(s) for MDD. Is clonazepam effective ? How about anticholinergics ? Antihistamines ? Phenytoin ? oxcarbamazine ? gapapentin ? (our guess -- clonazepam is effective, none of the others are reliable or significant).
- How does MDD and migraine interact ? Do medications for migraine reduce probability of MDD ? (our guess -certain ones -- venlafaxine -might help)
- What factors affect duration of MDD ? Does ongoing motion exposure that alleviates symptoms (i.e. driving) slow down recovery ? (our guess- yes)
- Role of physical therapy (if any) in MDD ? Compare vestibular physical therapy to strength training (for example). (our guess -- PT doesn't help)

Related Links:

There is a MdDs foundation, which maintains it's own website and quite active group of volunteers. The author of this page is loosely associated -- I sometimes provide some advice to this group.

- MdDs foundation sites and other related material
 - <u>MdDs Newsletter pdf (7/06)</u>
 - MdDs Newsletter pdf 9/06
 - <u>MdDs Newsletter pdf 10/06</u>
 - MdDs Newletter pdf 1/07
 - MdDs Newletter pdf 2/07
 - MdDs Newletter pdf 3/07
 - MdDs Newletter pdf 5/07
 - <u>www.groups.yahoo.com/group/mdds_support</u>
 - <u>www.nhffoundations.net/mdd</u>
 - <u>www.mddsfoundation.org</u>
- Surveys that the MdDs foundation would like you to take
- MDD page (Evan Torrie's page)

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