Mal de debarquement syndrome

Who is the leaflet for? What is its aim?
This leaflet is for patients in the Addenbrooke’s Hospital vestibular service experiencing dizziness and/or imbalance, who have been diagnosed with mal de debarquement syndrome, or have symptoms consistent with the diagnosis of MdDS but have not had a formal diagnosis. This leaflet aims to provide further information regarding this disorder and to provide sources of further information and support.

What is mal de debarquement syndrome?
Mal de debarquement means ‘sickness of disembarkement’ which refers to the feeling of movement felt after travel. Most people who have been on a boat will have experienced the sensation on returning to shore of feeling as if they are still on the boat. This sensation is normal and disappears after minutes, hours or a few days. A study of navy crew has shown that these sensations occur in around ¾ of individuals. In the vast majority of the navy crew the sensations disappeared within six hours and in all of them, the sensations resolved in less than two days.

If the sensation of movement persists for one month or longer after your journey, you may be experiencing the condition called either mal de debarquement syndrome (MdDS) or persistent mal de debarquement. In MdDS sensations of movement may last for months or up to a year or more.

One study suggests that episodes of MdDS last for between one month and one year in approximately half of cases and for more than one year in the other half of cases. This research also suggests that symptoms can return in many patients even without being provoked by another journey. Spontaneous recurrence of MdDS type symptoms was found to be much more likely to occur in patients with migraine compared to those without migraine.

Symptoms
MdDS patients most commonly describe the feelings of:

- Feeling as if they have just got off a boat, as if they are still on the boat
- Rocking or swaying
- Imbalance
- Visual motion sensitivity

Other symptoms can include:

- tilting
- nausea
- headache
- ear symptoms
In most patients the perception of movement, rocking or swaying is constant.\(^3\)

Most MdDS patients were not troubled with sea-sickness during their boat voyage or other motion experience.

Typically, symptoms may improve while travelling, such as during a car journey. The movement of the travel appears to counteract the movement the patient is feeling. One study has shown this to occur in \(\frac{2}{3}\) of patients.\(^2\) This differs from patients with motion sickness or vestibular disorders, who are often troubled by driving or car travel.

Some patients report their symptoms are worse with emotional or physical stress, particularly sleep deprivation and there are some reports of symptoms being worse with hormonal fluctuations.\(^2\)

Some patients report developing anxiety and/or depression due to either their continuing symptoms or a lack of diagnosis.\(^2\) Anxiety and depression are not seen as the underlying cause of the disorder, but a result of it.

**Causes**

MdDS will often be triggered by a long journey, typically a boat cruise, but sometimes also by flights or long car journeys. Symptoms may also appear spontaneously without any trigger event. MdDS that has recovered may recur after a further long journey.

The cause of MdDS is not fully understood and may vary between patients, however it is thought that MdDS may be due to the balance system not re-adapting to conditions back on firm land having got used to conditions during the journey.

Balance is normally maintained by combining information from three senses:

1. the balance organs in the ears
2. vision
3. input from sensations in the feet, muscles and joints

The brain will prioritise information from these three senses, based on the environmental conditions. For example, on a boat the balance organs in the ear are accurate, feet and muscle sensations are intermittently accurate, and the accuracy of visual input depends on whether a person is able to see the horizon. Some experts feel MdDS may be due to inappropriate weighting of this sensory information by the brain.\(^4,\,5\)

An alternative explanation suggests that patients with MdDS have developed predictive models of boat motion so that they don’t have to concentrate on their balance so much and also to avoid conflict between the three senses that causes motion sickness. Hain (2013)\(^5\) suggests that normally this ‘predictive model’ is discarded by the brain on returning to land but in individuals who develop MdDS for some reason the brain does not dispose of the strategy.
Cha et al. (2012) have reported changes in the areas of the brain related to vision, balance processing and emotional reactions in MdDS patients. It is unclear, however, whether these changes might be a cause of or result from the symptoms of MdDS, so further research is required.

**Diagnosis**

A diagnosis of MdDS is primarily based upon the patient history but also by ruling out other possible causes of symptoms.

MdDS can occur after a motion experience of two hours or more but more often the motion experience is of at least a week to trigger the disorder.

Further investigations may include one or more of the following, dependent on the individual case:

- Hearing tests.
- Vestibular (balance) assessment.
- MRI scan.

In MdDS these investigations would be expected to be normal, although it is always possible that incidental unrelated abnormalities may be found.

In some cases the patient history may be so clear no further testing is necessary.

**Treatment**

There is no known cure for MdDS and it can be difficult to treat. MdDS is sometimes termed a ‘self-limiting’ condition. This means it may resolve spontaneously without any treatment. Expert clinicians, however, feel that early management of the condition may improve the likelihood of better outcomes for the patient.

Some patients might benefit from vestibular rehabilitation exercises, especially for imbalance.

Many patients with dizziness or imbalance problems will consciously avoid unpleasant movements however this prevents the brain from habituating and becoming accustomed to them. Applied to MdDS patients this means that conscious avoidance of the unpleasant movement sensations associated with MdDS would not be a good idea. Some patients may be able to avoid the movement sensations of MdDS on travelling, for example when driving or by being driven, but it would not be advisable to seek out this experience too excessively.

Patients are advised to maintain normal levels of activity. Some form of regular exercise is recommended, although situations involving a possible sensory mismatch, such as on the treadmill, should be avoided as this may prolong symptoms.

There is no medication proven to treat MdDS. Some patients may benefit from medications such as a particular type of anti-depressant called a selective serotonin reuptake inhibitor (SSRI) or alternatively amitriptyline. Other medications that have
been tried include benzodiazepine, gabapentin, venlafaxine, phenytoin, or carbamazepine. Any decision to prescribe medication will be made by your ENT specialist/ neuro-otologist or medical doctor on an individual basis.

There is some evidence that a proportion of patients may be helped by a treatment involving certain head movements while in a moving visual field.

Other treatments that may be advised are stress reduction and regular sleep.

**Risks**

The risks associated with vestibular rehabilitation exercises are usually low. Your vestibular rehabilitation clinicians will aim to put together an individualised programme of exercises that you can carry out easily and safely.

Some exercises may not be suitable for patients with severe neck problems so the clinicians will assess your neck movements.

Some patients might find that balance exercises encourage too much attention on their symptoms, which may not be helpful to them. In this situation your clinician will monitor your progress and may advise changes to your exercise regime.

Any risks of medication will be assessed by your ENT specialist/ neuro-otologist according to your individual case and discussed with you as all medication has possible side effects. Please refer to the information from the manufacturer and raise any concerns with your doctor.

Risks of not seeking treatment are that symptoms may last for longer and the possibility of the development of anxiety and/or depression due to the continuing symptoms.

**Contacts/Further information**

Vestibular Audiologists, Audiology Department, Addenbrooke’s Hospital
Telephone: 01223 217797

Vestibular Physiotherapists, Neurophysiotherapy, Addenbrooke’s Hospital
Telephone: 01223 217568

Action for MdDS UK: http://www.actionformdds.org.uk/
MdDS Balance Disorder Foundation website: http://www.mddsfoundation.org/
Mal de Debarquement Syndrome (MdDS) website: http://www.mdds.org.uk/

**References/ Sources of evidence**


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