



MAL DE DÉBARQUEMENT SYNDROME (MdDS)

This handout is intended as a general introduction to the topic. As each person is affected differently, speak with your health care professional for individual advice.



Key points

- Means “sickness of disembarking.”
- Usually triggered by a long trip in a boat, car, train, or airplane.
- Most often affects middle-aged women.
- Not the same as motion sickness.
- Main symptom is a constant feeling of movement except during passive motion, such as being in a moving vehicle.
- Might be caused by a problem with the vestibulo-ocular reflex (VOR), hormone levels, or by a type of vestibular migraine.
- Usually a chronic condition, lasting weeks, months or even years.
- Treatment includes certain medications and vestibular rehabilitation (an exercise-based therapy).
- Several experimental treatments include the VOR protocol and brain stimulation.

What is mal de débarquement syndrome?

“Débarquement” is the French word for “disembarking” or getting off a boat, train, or airplane. “Mal de débarquement” (mal de DAY-bark-MAHN) means “sickness of disembarking”, also known as “land-sickness” — the opposite of seasickness. If you have ever stepped off a train, boat or car and felt as if the ground was rocking under your feet, you have felt mal de débarquement.

For most people, this feeling only lasts for a few minutes or hours. For some people, it may last for a few days or even weeks. But for some people, the feeling becomes chronic and lasts for a month or more. This is called mal de débarquement syndrome (MdDS).

MdDS seems to start in one of two ways:

- **Motion-triggered onset:** MdDS is usually triggered by a long trip at sea, such as a cruise. It can also be triggered after long trips by car, train, or airplane, or even space flight.
- **Spontaneous onset:** In some cases, it seems to happen without being triggered by motion.

Researchers are not sure how many people have MdDS. About 4 out of 5 people with MdDS are women, and the syndrome often develops between the ages of 40 and 50. MdDS can take a long time to diagnose, so it can be very frustrating for people who have it. It can seriously interfere with work and everyday life.

MdDS was defined as a disorder in 1987, but the symptoms were first described centuries ago.

What are the causes?

The underlying cause of MdDS is not clear. Scientists have several theories about what causes MdDS, including:

- a problem with the brain's vestibulo-ocular reflex (VOR)
- hormone levels
- a form of vestibular migraine

This question is still being studied. It is possible that several different things contribute to MdDS.

Theory: VOR problems

The brain's balance system combines information from many sources, including:

- * the vestibular system (the semicircular canals and otoliths in the inner ear), which senses when your head tilts, turns or changes speed
- * the visual system, which lets you see
- * the proprioceptive system, which sends signals about position, pressure, movement and vibration from the legs and feet and the rest of the body

Information from these systems is used by the vestibulo-ocular reflex (VOR). This reflex keeps your eyes steady even if your head is moving. For example, it enables you to focus on the words on this page even if you nod your head up and down or turn it from side to side. And when you walk, the VOR keeps your vision stable while your head bobs up and down.

Some researchers believe that MdDS develops when you turn your head from side to side while your body is rocking. They believe that the VOR starts to make the wrong decisions in response to particular signals from the vestibular and visual systems. This is known as maladaptation.

Theory: Hormonal factors

MdDS is common at around the age when many women are approaching menopause, and it often seems to be triggered when a woman has her period or when she stops taking hormonal contraceptives such as the pill. For many women, the symptoms

are worse during a menstrual period and better during pregnancy. All these factors suggest that changes in hormone levels, particularly lower estrogen levels, might be a factor in MdDS. Researchers are still exploring this theory and what it might mean for treatment of MdDS.

Theory: Vestibular migraine

Many people with MdDS also have migraine — one study found that 23% of people with motion-triggered MdDS and 38% of people with spontaneous MdDS also had migraine. Many of the symptoms related to MdDS are similar to migraine symptoms, including light sensitivity, nausea, and headache. For these reasons, some researchers believe that MdDS might be a type of migraine.

What are the symptoms?

The main symptoms of MdDS are constant feelings of rocking, bobbing, swaying, bouncing and being off balance, whether the person is walking, standing, or lying down. A key feature of MdDS is that these symptoms often get better while the person is experiencing passive motion, for instance being in a moving car or boat. Then the symptoms come back again when the person is back on solid ground.

People with MdDS often have other symptoms as well, including:

- sensitivity to light (photophobia)
- head pressure
- headache
- nausea
- “brain fog” or trouble thinking
- disorientation
- migraine
- fatigue
- insomnia (trouble sleeping)
- avoiding open spaces (agoraphobia)
- anxiety or depression

How is it diagnosed?

MdDS often takes a long time and many visits to diagnose, especially the spontaneous type. This can be very frustrating.

MdDS may be diagnosed by a primary care doctor, but it is more often diagnosed by a specialist, such as a neurologist, an otolaryngologist or an otologist.

Your doctor will ask about your symptoms. Try to be as specific as possible about your symptoms and when they get better or worse.

Your doctor will also ask about your medical history, including any medications you are taking or recently stopped taking. Your doctor will also do a thorough physical and neurological exam. Tests may include asking you to watch the doctor's nose while the doctor moves your head, or to watch your own thumbs while the doctor turns you in an office chair.

You may have some of the following diagnostic tests:

- vestibular function tests
- balance tests
- imaging (MRI scan)

In people with MdDS, these tests usually do not show anything wrong.

How is it treated and managed?

MdDS often goes away by itself in 6 months or less. Your doctor may suggest medication to make you more comfortable during this time. Some people also find that meditation, psychological counselling, good sleep hygiene and/or lowering the amount of stress in their lives help with their symptoms. Sometimes lifestyle changes that help with migraine are also helpful for MdDS.

Physical therapy seems to help some people with motion-triggered MdDS (56% in one study). It seems to be less helpful for people with spontaneous MdDS (only 15% in the same study). Vestibular rehabilitation also seems to help some people with motion-triggered MdDS (about

38%). The same study found that vestibular rehabilitation made some people's symptoms worse, and it did not help anyone with spontaneous MdDS.

Because we do not know much about the causes of MdDS, researchers are still trying to find the best ways to treat it. Several treatments are being studied.

Medication

Several different medications are used for MdDS. These medications often improve people's mood and quality of life, even if they do not help with the feelings of movement. They include:

- benzodiazepines (ben-zoh-dahy-AZ-uh-peens) such as clonazepam (kloh-NEY-zuh-pam) however, there is a risk of addiction with these medications
- antidepressants such as selective serotonin reuptake inhibitors (SSRIs), SSRIs in combination with serotonin-norepinephrine (sayr-uh-TOH-nin-NOR-eh-pih-NEH-frin) reuptake inhibitors (SNRIs), and tricyclic antidepressants
- anticonvulsants
- calcium channel blockers
- medications used for migraine, such as gabapentin (GA-ba-PEN-tin), amitriptyline (a-mee-TRIP-ti-leen), and venlafaxine (VEN-la-fax-een)

Certain medications that are used to treat motion sickness, known as vestibular suppressants, are not helpful for MdDS. They include meclizine (MEK-li-zeen) and transdermal (absorbed through the skin into the bloodstream) scopolamine (skow·PAA·luh·meen).

Vestibular rehabilitation

Vestibular rehabilitation is a type of exercise-based therapy. Its goal is to help your brain relearn how to balance and how to respond to signals from the visual, vestibular, and proprioceptive systems. A vestibular therapist can help you set treatment goals and design an appropriate program. But some

people find that vestibular rehabilitation makes their symptoms worse instead of better.

Vestibular rehabilitation for MdDS may include:

- Exercises to help reset the VOR
- Habituation, a type of rehabilitation that involves repeated, controlled exposure to things that trigger dizziness
- Balance exercises

It is very important to start exercises gradually and increase them slowly and steadily. Treatment may last for several months.

Experimental treatments

Treatments for MdDS that are still being studied include the VOR protocol and brain stimulation.

The VOR protocol tries to “reset” the vestibulo-ocular reflex. It uses special equipment to project vertical black and white stripes that are steadily moving sideways (an optokinetic stimulus). The person with MdDS watches these stripes while a healthcare professional rolls their head from side to side at the same speed as their rocking symptoms. Each session lasts about 3 to 5 minutes, and people have 1 to 8 sessions per day for up to 5 days. This procedure seems to help many people who try it, but some people find that their symptoms eventually come back. This treatment is still being studied and is only offered in specialized centres.

Repetitive transcranial magnetic stimulation (rTMS) is a form of brain stimulation that is being investigated for many different conditions, including migraine, tinnitus, and depression. A machine directs a series of short magnetic pulses at a specific area of the brain. This changes how the neurons in that area function. This treatment is still experimental for MdDS, but it may be possible to

enroll in a clinical trial.

Recurrence

MdDS can sometimes come back (recur) after it has gone away. Some researchers suggest taking very low doses of benzodiazepines before and during long trips by car, boat, train, or plane to prevent this. But this has not been formally studied in a clinical trial.

What to expect in the future

We still know very little about MdDS. It is not even clear whether motion-triggered and spontaneous MdDS are the same condition, or different conditions that cause similar symptoms. Scientists are studying many aspects of MdDS, including:

- what causes it
- why middle-aged women are at higher risk
- why many people have changes in thinking after getting MdDS
- the role of other related conditions such as visually induced dizziness, migraine, and depression
- the best way to treat MdDS
- why it sometimes comes back

With further study, we can hope to find answers to some of these questions.

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