MdDS can be diagnosed. **Share this brochure with your doctors and other health care providers.**

Frequently Asked Questions

Can I have MdDS without a motion event?

While MdDS most often presents after travel or a motion event, about 20% of cases occur without a prior motion trigger. Research to explore the underlying mechanisms of both onset types is on-going.

Will symptoms worsen if I travel?

Some patients travel with no increase in symptoms. Others experience increased symptoms that may or may not be temporary. Many describe a more prolonged period of symptoms with each MdDS episode. The general advice is to avoid potential triggers.

Find more FAQs on the About the Disorder & FAQ page of mddsfoundation.org.

Find Support

The MdDS Foundation provides a robust website with information about MdDS. In addition, we offer an online support group that unites the global MdDS community and is an easy way to connect with caring people who understand what it is like to live with MdDS. Learn more at **mddsfoundation.org/support**.

DONATE

Your donations advance research and awareness of MdDS.

Mail checks to:
MdDS Balance Disorder Foundation
Marilyn Josselyn, President
22406 Shannondell Drive, Audubon, PA 19403

Make secure online donations at
mddsfoundation.org/donate

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Additional brochures available by request to
brochures@mddsfoundation.org

Our Mission

Established as a 501(c)(3) in 2007, the MdDS Foundation promotes international awareness of and research on Mal de Débarquement Syndrome (MdDS). We advocate for and seek treatments to end the suffering from MdDS. We support research and studies that produce evidence-based findings, and seek to:

- provide support and education for patients and families of those with this rare disorder
- facilitate clinical studies designed to improve the diagnosis and treatment of MdDS
- promote basic and clinical research to better understand the underlying cause of this unique syndrome
- collect, collate, and distribute demographic and other information from those with MdDS via a patient registry and online surveys
- update and engage professionals who provide medical care and treatment to MdDS patients.

We are an *all-volunteer* nonprofit foundation and rely on volunteers to help accomplish our mission. All tax-deductible donations are directed to (1) informing health care professionals, patients, and the general public about MdDS, and (2) facilitating research towards effective evidence-based treatment, diagnosis, and prevention of this life-altering disorder.

MdDS Patient Registry: mdds.iamrare.org

Proud Member/Supporter

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MdDS Diagnostic Criteria
http://bit.ly/mddscriteria

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rocking swaying bobbing constant motion sensation
prolonged perception of movement like I'm on a boat
imbalance dizzy not spinning walking on a trampoline

Always feeling in motion?

You could be suffering from
Mal de Débarquement Syndrome

MdDS Foundation

Dedicated to finding the cause
and cure for MdDS

mddsfoundation.org

Diagnostic Criteria ▶ http://bit.ly/mddscriteria

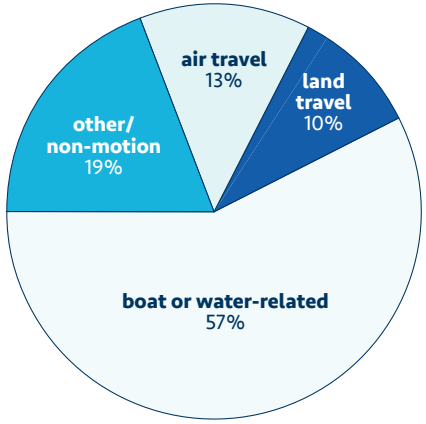
Mal de Débarquement Syndrome ICD Billing Codes
ICD-10-CM: R42 • ICD-11-CM: AB31.4

WHAT IS MdDS?

Mal de Débarquement Syndrome (MdDS) is a neurological disorder that leaves patients constantly feeling as if they are on a boat, rocking, bobbing, and/or swaying.

Sometimes called Disembarkment Syndrome, MdDS most often develops following a cruise or other type of water activity. It has also been reported following other passive motion experiences including air, train, and automobile travel. While MdDS most commonly presents after travel, for some onset appears without a motion event.

Events Associated with MdDS Onset



Symptoms of MdDS

Chronic perception of movement, as if on a boat, lasting for months to years including:

- Rocking
- Bobbing
- Swaying
- Gravitational pull

In addition to solid floors feeling like a trampoline, patients often report other symptoms. The phantom sensation of movement is often associated with:

- Imbalance
- Fatigue
- Anxiety
- Depression
- Headache
- Sense of unstable ground
- Cognitive impairment
- Difficulty concentrating
- Difficulty multitasking
- Visual motion intolerance

Symptoms may be made worse by stress, busy patterns, long narrow hallways or confined spaces, bright or flickering lights, virtual reality games, and scrolling on computer screens and mobile devices.

> The MdDS phenomenon is the natural result of the human brain adapting to environmental motion and is thus the quintessential neurological disorder.
>
> **YOON-HEE CHA, MD**
> **MdDS RESEARCHER**

Getting Diagnosed

MdDS is often diagnosed by a primary care provider, otolaryngologist (ENT), or neurologist. Based primarily on clinical history, they usually start by asking these questions.

- Do you feel like you are constantly rocking or swaying when you are not moving, and the only time it stops is when you are in motion (*e.g.*: driving or riding in a car)?
- Have movement sensations persisted for at least 30 days?
- Did you recently travel on a ship, boat, train, airplane, or experience other passive motion?

While there is no test that provides a definitive diagnosis, your doctor will probably want to eliminate similar disorders. A list of typical tests can be found on the Getting Diagnosed page of mddsfoundation.org. It may be helpful to note that, unique to MdDS, **symptoms temporarily go away when in passive motion**.

Managing MdDS

Relevant areas of the brain may be targets for neuromodulation therapy. However, no treatments or therapies have been found yet that are universally helpful.

- Medications that reduce anxiety and depression may provide relief from MdDS symptoms.
- VOR or OKN treatment may decrease symptoms.
- Some may benefit from vestibular therapy.
- Medications for motion sickness (anticholinergics) are not effective for either prevention or treatment of MdDS.

Innovative treatments are on the horizon. Increasing awareness among health care providers may lead to the clinical knowledge needed to develop effective treatment strategies.

MdDS diagnostic criteria are published in the *Journal of Vestibular Research*.

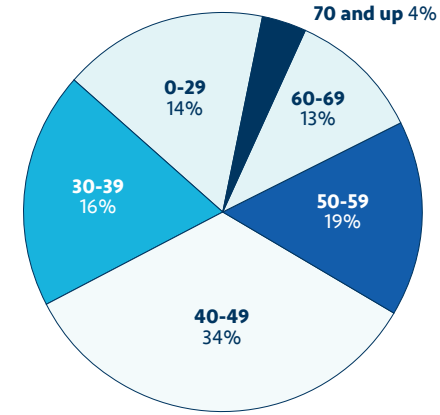
Duration & Severity

MdDS can persist for months or even years and may be quite disabling. Symptoms may vary in intensity, often disrupting daily life. Measure and monitor your levels with the 0-10 Symptom Severity Scale on mddsfoundation.org.

Prevention

Currently, no treatments or therapies can prevent the development of MdDS. Ongoing research continues to explore innovative therapies for the future. In the meantime, managing your lifestyle—such as reducing stress and ensuring you are well-rested both before and after travel—is a practical and important strategy.

Age at MdDS Onset



Tips for Living with MdDS

Like any chronic disorder, living with MdDS can be a daily challenge. To manage persistent symptoms, reduce stress, get plenty of sleep, and pay attention to symptom triggers. Focus on what you can do instead of what you cannot.

- Walking while focusing on the horizon is one of the best forms of exercise. Some find walking sticks, hiking poles or a cane helpful.
- A weighted vest or blanket may help you feel grounded.
- Some enjoy biking or skiing but may experience a rebound effect, a temporary increase in symptoms afterward.
- A shower stool, tub mat, grab bars, or clear shower curtain is helpful in the enclosed space of the shower.
- Some find benefit from vigorous exercise.

Find more Coping Tips, including travel advice, on the Living with MdDS page of mddsfoundation.org.