

MdDS can be diagnosed by informed health care providers. **Share this brochure with your doctors.**

Will symptoms worsen if I travel?

The general advice is to avoid potential triggers. Some patients have traveled with no increase in symptoms. However, some experience increased symptoms that may or may not be transient. Many describe a more prolonged period of symptoms with each MdDS episode.

- Some clinicians recommend benzodiazepines for travel, however clinical studies are needed to assess their effectiveness. Discuss medication options with your clinician.
- On long driving trips, the front seat is often better than the back. Stop every couple of hours to stretch your legs and take a break from the passive motion.

More travel advice and coping tips are shared on the MdDS Foundation website. Find them on the [Living with MdDS](#) page.

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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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.

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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>
ICD-10-CM Diagnosis Code R42

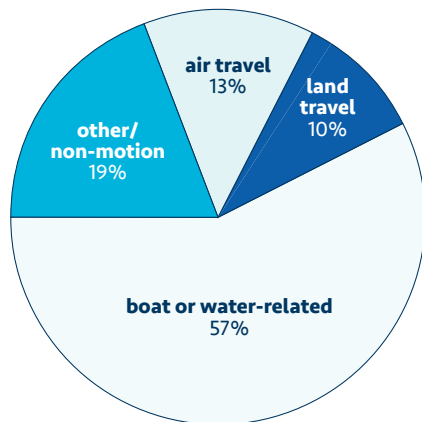
WHAT IS MdDS?

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



Sometimes called Disembarkment Syndrome, MdDS most often develops following a cruise or other type of water travel. It has 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

Constant sensation of motion, as if on a boat, lasting for months to years including:

- Rocking
- Bobbing
- Swaying
- Gravitational pull

Patients often report other symptoms. In addition to solid floors feeling like a trampoline, the phantom sense of motion is often associated with:

- Imbalance
- Fatigue
- Anxiety
- Depression
- Headache
- Unsteadiness
- Cognitive impairment
- Difficulty concentrating
- Difficulty multitasking
- Visual motion intolerance

Symptoms may be exacerbated by stress, busy patterns, long narrow hallways or confined spaces, bright or flickering lights, 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 usually diagnosed by a primary care provider, otolaryngologist (ENT), or neurologist. If you have symptoms of MdDS, ask these questions.



- Do you feel like you are constantly rocking and swaying and the only time it stops is when you are in motion (e.g.: driving or riding in a car)?
- Did you recently travel on a ship, boat, train, airplane, or experience other passive motion?
- Have the sensations persisted for at least 30 days?

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 often temporarily go away when in passive motion**.

Recently, MdDS diagnostic criteria were published in the *Journal of Vestibular Research*. See <http://bit.ly/mddscriteria>.

Treatment

No treatments or therapies have been found yet that are universally helpful.

- Patients may find relief with medications that reduce anxiety and depression.
- Areas of the brain in MdDS have been identified and may be targets for neuromodulation therapy.
- VOR or OKN treatment may offer relief for some.
- Some benefit from vestibular therapy or vigorous exercise.
- Medications for motion sickness (anticholinergics) are not effective for either prevention or treatment of MdDS.

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

Duration

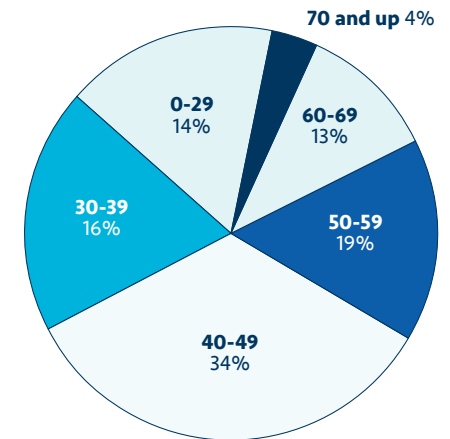
MdDS can persist for months or even years and may be quite disabling. Symptoms may vary in intensity and are highly variable for each individual. A Symptom Severity Scale can be found on the Symptoms page of mddsfoundation.org.



Prevention

No treatments or therapies prevent the development of MdDS. Medication such as benzodiazepines might be used prior to a motion experience. Reducing stress and being well rested prior to travel is important.

Age at MdDS Onset



Frequently Asked Questions

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

What are some coping tips?

Here are some tips from support group members for living with MdDS.

- 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 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.

Find more tips and Frequently Asked Questions on the About the Disorder & FAQ page of mddsfoundation.org.

mddsfoundation.org

