

MdDS can be diagnosed. **Innovative treatment options are being investigated.**

FAQ: Will symptoms improve/worsen if I go on another cruise?

The general advice is to avoid your onset trigger. Some patients have cruised/traveled again successfully (no increase in symptoms) but more often patients experience increased symptoms that may or may not be transient. Many describe a more prolonged period of symptoms with each episode.

- Discuss medication options with your physician. Some physicians suggest taking benzodiazepines during travel, however clinical studies are needed to prove their effectiveness across the population of MdDS sufferers.
- On long driving trips, stop every couple of hours to stretch your legs and reset your brain. The front seat is better than the back.

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

Support

Occurring in both genders and in all age groups, MdDS has been reported around the globe. Our online support groups unite our community and offer an easy way to connect with caring people who understand what it is like to live with this disorder. 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

This brochure is provided as an educational service by
The MdDS Foundation



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:

- facilitate clinical studies designed to improve the diagnosis and treatment of MdDS,
- promote basic and clinical research to better understand the cause of this unique syndrome,
- collect, collate, and distribute demographic and other information from those with MdDS via online surveys (at present, our findings represent the world's largest available database about this patient population),
- update professionals who provide medical care and treatment to MdDS patients,
- provide support and education for patients and families of those with this rare disorder.

We are an *all-volunteer* nonprofit foundation. 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.

mddsfoundation.org [mddsfoundation](https://twitter.com/mddsfoundation)

GuideStar registered 501(c)(3) nonprofit

Resources

National Institutes of Health/Office of Rare Diseases Research
<http://rarediseases.info.nih.gov>

National Organization for Rare Disorders (NORD):
www.rarediseases.org

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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

Imagine
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

ICD-10-CM Diagnosis Code R42

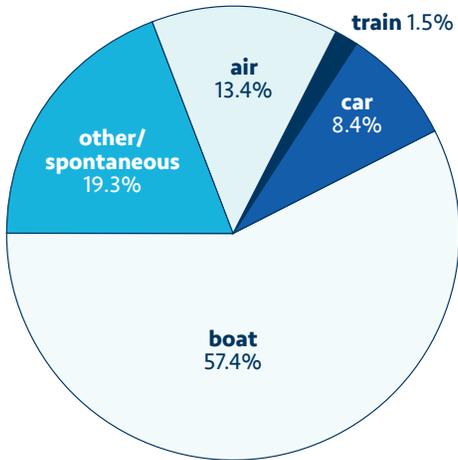
WHAT IS MdDS?

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



Sometimes called Disembarkment Syndrome, MdDS most often develops following a cruise or other type of water travel. MdDS has also been reported following air, train, and automobile travel; and less commonly after repeated elevator use, walking on docks, from the use of virtual reality equipment, or practically any motion experience. While MdDS most commonly presents itself after travel, for some onset appears to be spontaneous or without a motion event.

Precipitating Event with MdDS Onset



Symptoms of MdDS

Persistent sensation of motion and imbalance lasting for months to years such as:

- Rocking
- Bobbing
- Swaying
- Disequilibrium
- Unsteadiness
- Sense of unstable ground

In addition to the rocking, bobbing, and/or swaying, there are many secondary symptoms. The sensation of motion is often associated with:

- Anxiety & Depression
- Difficulty concentrating
- Difficulty multitasking
- Visual motion intolerance



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, ENT, or neurologist. Use the Find a Doctor tool on our website to locate one who is familiar with MdDS nearby. You'll find it on the Living with MdDS page.



Presently, there is no test that can provide a definitive diagnosis, but MdDS may be diagnosed using patient history (such as a recent travel or other motion experience) and the elimination of other disorders. Your doctor will probably order tests including but not limited to:

- Nystagmus testing (ENG, VNG)
- Evoked potentials (AEP) or VEMP
- Brain scans (CAT, MRI, MRA)

Consult your physician to determine which, if any, tests are best for you. It may be helpful to note that, unique to MdDS, symptoms often temporarily remit when in passive motion, *e.g.*: driving or riding in a car.

Duration

The effects of MdDS may be quite disabling and can persist for months or even years. Symptoms may vary in intensity and are highly variable for each individual.



Treatment

Some success in managing symptoms has been realized with benzodiazepines, SNRIs, SSRIs and sometimes tricyclics. Anticholinergic medications that work for typical forms of dizziness and motion sickness, *e.g.*: meclizine or scopolamine, are not effective in either treatment or prevention of MdDS.

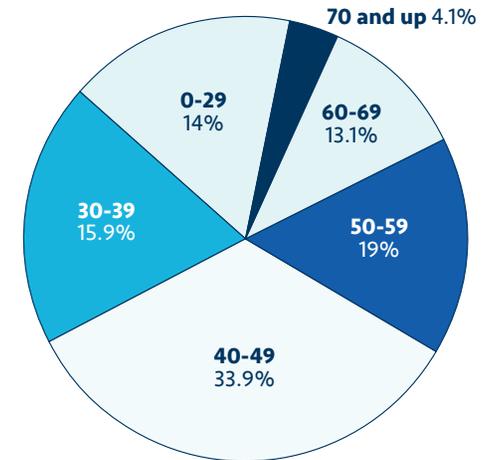
Innovative treatments are on the horizon. Increased awareness among physicians may lead to the clinical knowledge needed to develop effective treatment strategies. Please share this brochure with your doctor.

Prevention

There is no known clinical study regarding the prevention of MdDS. Medication such as benzodiazepines might be used prior to the motion experience. Reducing stress and being well rested prior to travel is important. For persons with a history of MdDS, avoiding further exposure to rocking motion is recommended, as many patients report recurrences.



Age at MdDS Onset



Coping Tips

Like any other 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.

FAQ: What treatment or therapy is there?

At present there are no treatments or therapies proven to be universally helpful. Some individuals benefit from medications. Vestibular rehabilitation therapy has been effective for a small number of patients.

- Walking while focusing on the horizon is one of the best forms of exercise. Some find walking sticks, hiking poles or a cane helpful.
- Some enjoy biking or skiing but may experience a rebound effect, a temporary increase in symptoms afterward.

Check with your doctor before beginning any diet or exercise program.

Find answers to more Frequently Asked Questions on the About the Disorder & FAQ page of our website.