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

#### FAQ: Will symptoms worsen if I travel again?

The general advice is to avoid your onset trigger. Some have 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 shared 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 group unites our community and offers an easy way to connect with caring people who understand what it is like to live with MdDS. Learn more at mddsfoundation.org/support.

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. EIN: 20-5953110

#### **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 X mddsfoundation



Resources

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

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Additional brochures available by request to brochures@mddsfoundation.org

rocking	swaying	bobbing	constant motio	on sensation
prolonged	perception	of moveme	ent like I'm	on a boat
imbalance	dizzy r	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

Diagnostic Criteria ► http://bit.ly/mddscriteria ICD-10-CM Diagnosis Code R42

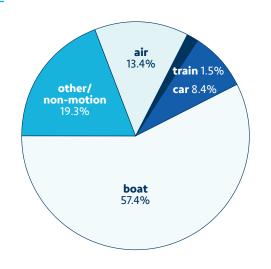
#### WHAT IS MdDS?

Mal de Débarquement Syndrome (MdDS) is a neurological disorder that leaves patients 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. 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 to be 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
- Gravitational pull
- Unsteadiness
- Sense of unstable ground

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

- Fatigue
- Anxiety & Depression
- Difficulty multitasking
- Cognitive impairment



The MdDS phenomenon is the natural result of the human brain adapting to environmental motion and is thus the guintessential neurological disorder.

> YOON-HEE CHA. MD MdDS RESEARCHER

#### **Getting Diagnosed**

MdDS is usually diagnosed by a primary care provider, ENT, or neurologist. A diagnosis can be made quickly using patient history such as recent travel or other motion experience, even virtual, and asking:

- Do you feel a constant sense of motion, as if on a boat?
- Does the sensation go away when you are back in motion?

MdDS diagnostic criteria can be found in the Journal of Vestibular Research at http://bit.ly/mddscriteria.

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 our website. You should discuss which, if any, are best for you. It may be helpful to note that, unique to MdDS, symptoms often temporarily go away when in passive motion, e.q., driving or riding in a car.

#### 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.

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#### 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. Increasing awareness among physicians may lead to the clinical knowledge needed to develop effective treatment strategies. Please share this brochure with your doctor.

#### mddsfoundation.org

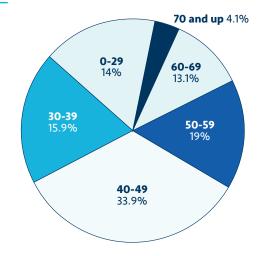
#### Prevention

There is no known clinical study regarding the prevention of MdDS. Reducing stress and being well rested prior to travel is important.



Medication such as benzodiazepines might be used prior to a motion experience. For persons with a history of MdDS, avoiding further exposure to rocking or oscillating 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.

- Difficulty concentrating
  - Visual motion intolerance

