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Cruise triggers rare disorder for Spring resident

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Choppy seas and 15-foot waves transformed a well waited cruise from Galveston to Cozumel into a bobbing fiasco for Spring resident, *Terri Gibson*. Even after landfall, her head felt as it did on the sea, constantly in motion.

A primary care physician prescribed medication which helped little. It wasn't an ear infection. And, an MRI came back normal. A dead end to no answers fueled research of her symptoms where she located a specialty doctor at the Baylor College of Medicine.

A series of grueling rotary, choleric and hearing tests revealed that she was suffering from a rare balance disorder called mal de debarquement syndrome.

Motion stimulates MDDS - particularly cruises, planes, amusement park rides, trains, long car trips, sailing, and speedy elevators - and 95 percent of sufferers are women.

"When I walk, I feel like I am walking on a trampoline. When I lay in bed, I feel like I am on the cruise ship just rocking from side to side," Gibson said.

To keep her balance she has to hold onto something and if she's seated for too long her head will start to bob up and down. Patients experience brain fogs or difficulties concentrating, memory loss, fatigue and little success with multi-tasking.

Commonalities of shopping centers and the workplace have become much harder to endure too. Florescent lights, enclosed areas, stress, computers, social environments, and the turmoil of traveling up and down an aisle are a nightmare.

Eight-year sufferer Marilyn Josselyn said it wasn't a rough cruise which ailed her; it was her brain's inability to readapt on land.

"Here I am rocking away, brain rocking," she said. "But, I'm not moving."

Many patients lose their jobs and encounter difficulties with insurance companies because MDDS fits into a spectacle of some 6,000 other named rare disorders. Originally, doctors perceived it as something psychological or hormonal because trying to diagnose it is exceedingly difficult and most are unaware of it generally speaking.

Equally puzzling is the reality that 99 percent of patients only feel motionless while moving in a vehicle.

"It's really weird how my system can't figure out how I'm not in a boat anymore. When I'm moving I'm fine, but I can't sit for too long or stand. Sometimes my head bobs up and down, and then my whole body will move with it," Gibson said.

Medication is the only resolve to MDDS, but strong doses cause fatigue and other side effects. However, physicians continue to make strides in the syndrome.

Upon the discovery of MDDS, Josselyn's husband founded a Web site, www.nhfffoundations.net/mdds, to assist other sufferers. MDDS is listed among others in the National Organization for Rare Disorders.

Today, more than 300 patients support a Yahoo group exchanging helpful tips on coping, details about prescribed medications and personal stories.

Comments about this article can be sent to kdockery@hcnonline.com.