EDUCATING FAMILY/FRIENDS ON VESTIBULAR DISORDERS: WHAT TO EXPECT

• Symptoms can be mild, moderate, or severe, and vary at any given time. They include spinning sensation, imbalance, lightheadedness, nausea, wooziness, etc. Symptoms are not as basic or as minor as the sensation you have when getting off a rollercoaster or a spinning ride. Some people feel this movement internally, while others feel like the environment surrounding them is moving.

• Symptoms can come and go or be more constant. Some conditions cause episodes that may occur daily, weekly, monthly, or yearly. Many disorders are chronic and may affect an individual for life.

• Some symptoms can be predictable with certain triggers, like riding in the car, using a computer, eating a certain food, or going to the grocery store. Other symptoms can come without warning and are totally unpredictable.

• Vestibular disorders can be complex, not only to you and me, but also to the medical community.

• Vestibular disorders are “invisible” to the naked eye. Just because a person doesn’t look sick doesn’t mean that they don’t feel sick.

• It is helpful for family to accompany their loved ones to doctor’s appointments, both because it can be difficult for the patient to remember everything the doctor says and so that you hear directly from a trusted source what is going on.

• Individuals experience both good days and bad days, which are often unpredictable and variable. Because of this, it is often difficult to make plans, attend social commitments, and go to work on a consistent basis. Individuals sometimes have to leave an event early or cancel due to their symptoms.

• Bright lights, busy environments, riding/driving in a car, and loud conversations can all make symptoms worse.

• Vestibular disorders can cause significant cognitive deficits. Individuals can be forgetful, show slowed thinking, have trouble multi-tasking and performing complex tasks, and be easily confused. At the peak of an attack, a vestibular patient may not be able to communicate what is going on for them.

• Anxiety and stress can exacerbate dizziness and make symptoms worse.

• Because those with vestibular disorders spend so much time and effort focused on staying upright and controlling their vertigo, they are often very fatigued and tired. This can be misinterpreted as simply being lazy. They often wake in the morning with their energy tanks only half full. Adequate sleep and pacing activities are extremely important.