VESTIBULAR
DISORDERS ASSOCIATION

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Caregiver Survey Results

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MOST CHALLENGING IMPACTS OF VESTIBULAR DISORDERS

There are several impacts which were often mentioned as the most challenging, limiting or disruptive both for the vestibular patient and for the family members.

Hearing loss

- *It is frustrating for them when I can't hear them and I ask them to repeat themselves.*
- *Even with my hearing aids I still have difficulty understanding what is being said, so many times I just fall silent.*

Many of the responses identified hearing loss as the most difficult impact of their vestibular disorder on their family and friends. When they cannot participate in conversations they are isolated and removed from family events even when they are present. It is necessary for family members to speak in a certain ear, speak more clearly, and often repeat what they say. Even with hearing aids, it is hard to maintain the same easy, spontaneous relationships as before.

Unpredictability of symptoms

- *My illness has affected my family because I never know when I am going to have an attack.*
- *Sadly, many friends have moved on because I cannot participate in activities.*

Many responders noted the difficulty of making any plans because they are never certain how they are going to feel from day to day or hour to hour. This unpredictability makes it difficult to schedule events, accept invitations, and travel. Even when vestibular patients feel fine at the start of an event, they may have to leave early. As a result, the range of social interactions with family and friends becomes limited. Spouses are unable to travel and enjoy outings, daughters are unable to have their mothers babysit for their children, and friends can no longer share favorite activities.

Loss of the person they used to know

- *I believe they are saddened by this disease because I used to be a vibrant, confident person and now that person is gone.*
- *I want the other me back and I don't know how to find him.*

We all enjoy certain hobbies and activities – golf, swimming, dancing or riding a bike. Most of us work, go out to eat, and attend concerts or church services. Quite often a vestibular disorder greatly reduces or eliminates the ability to enjoy these activities. This impacts the vestibular patient, and it also impacts the family members and friends who enjoyed these activities as well. On a more personal level, vestibular patients are quieter, more withdrawn, and can be more tentative or nervous. These are monumental changes, and it is no surprise that many responders listed the sadness of their friends and family at losing the person they knew and loved as the most significant impact of their illness.

Anxiety and constant worry

- *My wife and my kids and grandchildren are always on alert for my next fall.*
- *My husband cried when my neuro-otologist announced that there was nothing further he could do for me.*

Vestibular patients can experience sudden and frightening symptoms that alarm their friends and family. If someone experiences sudden falls, everyone is on “high alert” when they accompany them. Some environments, like a large, crowded store, can trigger “attacks” and patients need to lie down on the floor or escape rapidly. When a friend or family member does not know how to help their loved one it is scary and upsetting. When your family member is sick for months with no diagnosis and no remedies, you feel sad, worried and upset.

Limits and needs

- *Accommodations are made for me as to the timing of events and places we go.*
- *We can’t do all the things that other couples do. I feel lonely as I watch everyone else “live.”*

Every response discussed new limits on their life and the difficulty of adjusting to those limits on their part and the part of family members. Quite often the new limits are a surprise and adjusting to the new situation involves much trial and error. When your abilities change, everyone around you is forced to adjust – but they don’t know how. This can cause discomfort and stress for everyone involved.

Other Impacts

There were other important impacts noted by a small number of respondents. First, the financial impacts of loss of work and the cost of treatment add a definite stress to the family, compounding other issues. Several vestibular patients mentioned their inability to concentrate or to track a conversation as an alarming symptom for loved ones. Patients also noted that the long list of odd and unpredictable symptoms caused others to question whether they were really sick, since they appeared on the outside to be fine. And several vestibular patients noted the disappointment and sadness of their family when doctors were unable to diagnose or offer any help.

ADJUSTMENTS TO IMPACTS OF VESTIBULAR DISORDERS

- *I believe if you have a disease, the hardest thing is getting people to understand what you are dealing with. That's the first step in helping your situation and in helping the people around you.*

This insightful quote reflects both an understanding of the limits on the part of the vestibular patient as well as problem solving about adjustments that will help with family and friends. Some patients and their families are finding creative ways to adjust to the new limits of having a vestibular disorder. In many cases caregivers were specific about the kinds of adjustments they have made to make life easier for their spouse/friend, and to feel like they are participating in a solution.

Driving

Many vestibular patients no longer drive or limit their driving because repeatedly turning their head or moving their focus is a challenge. As a result, caregivers do most of the driving. When vestibular patients can clarify what they need, and caregivers understand how to adapt, their driving can more closely match the needs of the vestibular patient. For example, they drive more slowly, take turns slowly, and avoid windy roads. Parking lots are another vestibular challenge and caregivers learn to park in the first spot in the parking lot to avoid turning and looking for spots. Parking garages are often too challenging. One person even noted that she gets out of the car when it is necessary for the driver to back up. These adjustments make all outings more tolerable and symptom free.

Dining out/social settings

There are a number of adjustments that can help in social situations. For example, if the vestibular patient is seated at a table so they can hear better, they will be able to stay at an event longer and enjoy it more. It is also preferable for a vestibular patient to sit so they are not facing a crowded room where they will see constant motion. A quiet restaurant with seating in an out of the way area is another good strategy. In addition, having an understanding (or even a signal) about when the vestibular patient needs to leave an event removes any pressure to try to stay or to avoid inconveniencing others by needing to leave. Some loud, crowded, or motion oriented events need to be avoided entirely. As one caregiver stated, "We have to plan events and outings to take my wife's vestibular condition into consideration and the fact that she tires easily."

Speaking

The main way that friends and family have adjusted to hearing loss is to speak clearly and directly. It is challenging to remember to speak only when you are in the same room, facing someone, or to speak on their "hearing side." It is unnatural to speak in a louder or slower voice than normal. Even the most dedicated caregivers identify hearing limitations as the hardest adjustment to remember and manage.

Travel

Many vestibular patients are challenged by riding in a car and flying and have limited ability to travel. Several people mentioned needing one to several days to recover after traveling. Friends and family need to adjust to this schedule. There are also trip lengths and locations that are more challenging and need to be avoided. For example, very hot climates might cause dehydration and vestibular episodes. The destination, types of events, and the travel schedule need to be planned to accommodate the impacts on vestibular disorders.

Walking

Several important adjustments were noted to assist vestibular patients with challenges when walking. First, vestibular patients need to walk in certain locations – on the left or right - to avoid turning their head in challenging directions. Also, it is very helpful for friends and family to be on the side where vestibular patients can hear the best. Other walking challenges involve slippery or uneven surfaces, poor lighting, and walking in crowds. Friends and family learn to offer an arm when needed. One patient appreciated that: "My husband is my "blocker" as I walk through a busy environment so that I can look down as I maneuver."

IN CONCLUSION

As always when I reach out to our members, I am inspired by the responses I receive. The struggle with vestibular disorders is so daunting and demands a great deal from both patients and family. The growing understanding of vestibular impacts and the adjustments that families make to cope with the needs of their loved ones is often heroic. One caregiver made the following comment: "There is nothing that I consider most difficult for me, except what I want for her, to get healthier and feel more like "before." She is a trooper though, a real champion." It is these insights and this dedication that motivates me to increase VEDA's impact.