



# VESTIBULAR

---

## DISORDERS ASSOCIATION

5018 NE 15<sup>TH</sup> AVE · PORTLAND, OR 97211 · FAX: (503) 229-8064 · (800) 837-8428 · INFO@VESTIBULAR.ORG · VESTIBULAR.ORG

## Understanding Vestibular Disorders as an Invisible Chronic Illness

*This outline for a support group meeting was submitted by a seasoned support group leader on VEDA's Resource Lists. She reports that this framework was inspired by chapter three of the book, *Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness* by Paul J. Donoghue, PhD and Mary E. Siegel, PhD. 2000, W. W. Norton & Co., Inc. New York, NY, p.284.*

### **What is an Invisible Chronic Illness?**

Discussion: What is an Invisible Chronic Illness (ICI)? How does it differ from an acute illness with visible symptoms, such as cancer? Ask the group to list some common ICIs. (Examples might include: irritable bowel syndrome, HIV, endometriosis, migraine, arthritis, or multiple sclerosis.) Ask if group members know people with such common ICIs and, if so, how do they empathize with these people? Since experiencing a vestibular disorder, have group members' empathy increased for people with other ICIs?

### **Similarities and Differences of ICIs**

Discussion: Ask the group to describe the similarities and differences among the ICIs identified above. Similarities might include: the person looks fairly well, the symptoms aren't visible, the person visits many doctors, the illness is difficult to diagnose, and the symptoms are non-measurable/hard to quantify with a medical test. Examples of differences are that while chronic, some ICIs have more serious consequences than others in the long-term and sympathy levels vary.

### **Society's Views about ICIs and Vestibular Disorders**

Discussion: According to *Sick and Tired of Feeling Sick and Tired*, "the degree of mental anguish that an individual will suffer from his illness, as well as the amount of care, trust, respect, and compassion he will receive, is dependent upon three factors outside of himself: the social acceptability of the illness; the clarity of diagnosis; and the potential severity of the illness" (pg. 40). Ask group members to consider how these factors apply to vestibular disorders relative to other ICIs.

**(A) Social acceptability** - Ask the group to rank certain ICIs, including vestibular disorders on a scale ranging from low to high social acceptability. For example,



# VESTIBULAR

---

## DISORDERS ASSOCIATION

5018 NE 15<sup>TH</sup> AVE · PORTLAND, OR 97211 · FAX: (503) 229-8064 · (800) 837-8428 · INFO@VESTIBULAR.ORG · VESTIBULAR.ORG

irritable bowel syndrome might rank “low,” while multiple sclerosis might rank “high.” Illustrate the consensus by drawing a scale on a flip chart or white board. Then ask how society perceives people who exhibit common symptoms of vestibular disorders such as unsubstantiated fatigue, unsteady gait, or lack of concentration. Does having a visible sign, such as a cane, increase social acceptability?

**(B) Clarity of Diagnosis** - Using the drawing board, have the group rank vestibular disorders and other ICIs on a scale of low to high diagnosis clarity. For example, chronic fatigue syndrome might rank “low” and arthritis might rank “high.” Ask the group how society perceives people who have a vestibular disorder with an unknown diagnosis for a long length of time or a diagnosis that is poorly understood or debated by society as legitimate.

**(C) Potential (life-threatening) severity** - Using the drawing board to help illustrate, have the group rank the potential severity of vestibular disorders and other ICIs. An ICI such as migraine might rank “low,” while HIV might rank “high.” Ask the group to discuss the level of empathy for ICIs that rank high as opposed to those that rank low. Where do vestibular disorders fall in this ranking?

### **Context and overall learning points**

Discussion: Ask if the context of A, B, and C above helps group members understand why their family, friends and co-workers may not empathize with them about their vestibular disorder as much as hoped. Using the drawing board to record the responses, ask the group to identify specific strategies for helping other people to better understand and empathize with a person who has a vestibular disorder.