



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:

- Irritable Bowel Syndrome
- Autoimmune
- Endometriosis
- Rheumatoid and osteoarthritis
- Celiac disease
- Fibromyalgia
- Chronic Fatigue Syndrome
- Mental and Psychiatric Illness'
- Lyme Disease
- Epilepsy

Ask if group members know people with such common ICIs. If they do, how do they show your empathy?

- Listen to the person without being judgmental
- Understand and accept you cannot change their diagnosis, but can still make a difference by offering your time to let the person express their pain, suffering and emotions about their illness.
- Research the illness and become familiar with the symptoms and treatments so you better understand what they are doing thru.
- Consider what it would feel like to be going thru what they are going through.
- If you have questions ask them. To assume is not the answer, everyone is different.
- Spend time with them doing activities that they can do, such as:
 - Watching a movie
 - Getting a bite to eat, cook together or for them a meal they really like
 - Take a walk together or take them for a walk even if it's in a wheel chair

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- Drive them somewhere like a park or where they need to go for errands or to visit one of their friends they might like to see as well.
- Spend time helping them with a creative project
- Go thru photos together and reminisce

Discussion: Ask the group experiencing their vestibular disorder, have they noticed their empathy has 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:

- They look fine on the outside because their symptoms are not visible
- They have many Dr. visits
- Their illness is difficult to diagnose
- Their symptoms are non-measurable and hard to quantify with a medical test
- While chronic, some ICIs have more serious consequences than others in the long-term

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 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 the diagnosis
- The potential severity of the illness" (pg. 40).

Discussion: *Ask group members to consider how these factors apply to vestibular disorders relative to other ICIs.*

SOCIAL ACCEPTABILITY

Does having a visible sign, such as a cane, wheel chair, visible scars, a limp red face, brace, sling, increase social acceptability?

Discussion:

Ask the group how society perceives people who exhibit common symptoms of vestibular disorders such as:

- Unsubstantiated fatigue
- Unsteady gait

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- Lack of concentration

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 the group if talking about the way others view ICI's helps them to understand how family members, friends and co-workers perceive their vestibular disorder.*

IDENTIFYING STRATEGIES

Discussion: Ask the group to identify specific strategies for helping other people to better understand and empathize with a person who has a vestibular disorder.

- Communicate how you feel emotionally and physically.
- Give them VeDA articles so they can learn about your illness.
- Take them to a support group to listen to others' struggles.
- Have them watch a YouTube video from a patient's point of view, and a professor/researcher's presentation on the disorder.
- Invite them to your doctor visit.
- Make a list and write down 10 things you want others to know about your disorder.