



Support Group Discussion: Becoming a Vestibular Advocate During Balance Awareness Week

Discussion Goal:

Help participants recognize that they have the power to improve the lives of other vestibular patients through awareness and advocacy, while introducing Balance Awareness Week as an opportunity to take action.

1. Welcome & Icebreaker (5 minutes)

One of the things I've learned from working with the vestibular community is that every patient has the potential to be an advocate, even if they don't think of themselves that way. Advocacy doesn't have to mean speaking at conferences or meeting with lawmakers. Sometimes it's as simple as sharing your story with a friend, helping someone understand what a vestibular disorder really is, or pointing a newly diagnosed patient toward reliable resources. Those small conversations can have a ripple effect, helping more people recognize vestibular disorders, reducing stigma, and making it easier for future patients to find the care they need. That's really what Balance Awareness Week is all about—giving our community an opportunity to work together, each in our own way, to make vestibular disorders more visible and help others understand the challenges we face every day.

Opening question:

"When was the first time you realized that most people don't understand what it's like to live with a vestibular disorder?"

Allow participants to share a few examples.

Transition:

One of the biggest challenges of living with a vestibular disorder is that it's largely invisible. Most people have never heard of the vestibular system, and even many

healthcare providers receive limited training in diagnosing and treating vestibular disorders. That's why awareness matters.

2. Why Is Vestibular Awareness Important? (10 minutes)

Discussion Questions

- Why do you think vestibular disorders are so poorly understood?
- Have you ever felt that someone didn't believe or understand what you were experiencing?
- What misconceptions have you encountered about dizziness or balance disorders?
- What do you wish your family, friends, employer, or healthcare providers understood?

Key Discussion Points

- Vestibular disorders affect millions of people but remain relatively unknown.
 - Symptoms are often invisible.
 - Many patients spend months or years seeking an accurate diagnosis.
 - Lack of awareness contributes to delayed diagnosis, limited access to specialists, social isolation, and misunderstanding.
 - Increasing awareness helps improve recognition, diagnosis, treatment, and support.
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3. What Does Patient Advocacy Mean? (10 minutes)

Transition:

When people hear the word "advocacy," they often think about politics or lobbying. But advocacy happens every day in much smaller—and often more powerful—ways.

Discussion Questions

- What does advocacy mean to you?
- Have you ever advocated for yourself during a medical appointment?
- Have you ever helped another vestibular patient?
- Have you ever educated someone about vestibular disorders?

Key Discussion Points

Advocacy can include:

- Learning about your condition.
- Asking questions during medical appointments.
- Sharing reliable educational information.
- Supporting another patient.
- Participating in research.
- Educating family, friends, employers, or healthcare providers.
- Sharing your personal story.
- Volunteering or supporting organizations working to improve vestibular care.

Remind participants that advocacy doesn't require being an expert—it starts with sharing lived experience.

4. Why Your Story Matters (10 minutes)

Discussion Questions

- Have you ever shared your vestibular story with someone?
- What happened when you did?
- Was there someone else's story that helped you during your own journey?

Key Discussion Points

Stories help people understand what facts alone cannot.

Stories:

- create empathy
- reduce stigma
- help newly diagnosed patients feel less alone
- educate healthcare providers
- inspire hope

Emphasize that every person's journey is different, and every story adds another perspective to the larger picture of living with a vestibular disorder.

5. Introducing Balance Awareness Week (10 minutes)

Transition:

One of the biggest opportunities each year to raise awareness is Balance Awareness Week.

Explain that Balance Awareness Week is a time when the vestibular community comes together to:

- educate the public
- increase awareness of vestibular disorders
- encourage earlier diagnosis
- connect patients with resources
- highlight research and advocacy efforts

Ask participants:

- Had you heard of Balance Awareness Week before today?
 - Why do you think having a dedicated awareness week matters?
 - What kinds of awareness activities have you participated in before?
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6. How Everyone Can Participate (15 minutes)

Rather than asking, *"Can I make a difference?"* ask:

"What's one thing I feel comfortable doing?"

Option 1: Share Educational Resources

- Share an article or infographic on social media.
- Post a short educational video.
- Help friends understand what vestibular disorders are.
- Share reliable information instead of misinformation.

Discussion prompt:

Which topics do you think people most need to learn about?

Option 2: Share Your Story

Encourage participants to share as much—or as little—as they feel comfortable.

Ideas include:

- a social media post
- a short video
- a photo with a caption
- a blog post
- speaking to family or coworkers

Discussion prompt:

What is one thing you wish someone had told you when you were first diagnosed?

Option 3: Create a Peer-to-Peer Fundraising Page

Explain that fundraising is another form of advocacy.

Instead of simply asking people to donate, participants can:

- tell their vestibular journey
- explain why awareness matters
- invite friends and family to support the cause
- help fund education, support programs, research, and advocacy

Discussion prompt:

How might sharing your story through a fundraiser help someone else?

Option 4: Become an Everyday Advocate

Examples include:

- participating in support groups
 - volunteering
 - participating in research studies
 - educating healthcare providers
 - encouraging someone who's newly diagnosed
 - correcting misinformation when they encounter it
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7. Reflection & Personal Commitment (10 minutes)

Ask each participant:

"What's one thing you could do during Balance Awareness Week to help make vestibular disorders more visible?"

Responses might include:

- Share one educational post.
- Tell my story.
- Invite someone to learn about vestibular disorders.
- Create a fundraiser.
- Talk to my employer.
- Reach out to another patient.
- Volunteer.
- Participate in a research study.

Reinforce that there is no "right" way to advocate—every action helps.

Closing Thought

Every person in this room knows something that the rest of the world doesn't: what it is like to live with a vestibular disorder. That lived experience is powerful. By sharing our stories, educating others, supporting one another, and participating in Balance Awareness Week, we can help ensure that future patients are diagnosed sooner, understood more fully, and supported more effectively. Advocacy isn't about having the loudest voice; it's about using the voice you have to help make vestibular disorders visible.