



FOR MY FAMILY AND FRIENDS

It's natural to want to be supportive and encouraging when a friend or loved one is suffering. There are a few "Dos and Dont's" that fellow vestibular and balance disorder sufferers wish family and friends knew.

DO'S

- **Be a good and active listener.** We want to know you care and sometimes we simply need to talk, for no other reason than to vent, but also understand that there may be times we are too exhausted to hold a conversation.
- **Reach Out.** Whether that's by text message, email, card or social media in-box. Let us know you are thinking about us and that you care (prayers are welcome to). You don't have to say much.
- **Just Do It.** Please don't ask if there is something you can do - just do it. We don't want to be a burden and will most likely say no, if you ask if we need something. Instead we would welcome you dropping off a meal, asking to take care of the children for a couple hours, or reach out to our significant other and ask what you can do.
- **Go to appointments.** This is always helpful, especially if we aren't feeling well, we can forget to mention a new symptom or forget something the physician mentions. In addition, you may gain more understanding about our illness and symptoms.
- **Research the symptoms or diagnosis.** You can find more information on symptoms, vestibular and balance disorders here: vestibular.org/fsn.
- **Understand,** symptoms can change daily and moment to moment.
- **Invite Me.** It's wonderful to be invited to family gatherings and other events, but please understand we may not show, even if we say we will. Our symptoms control our lives moment to moment. If we do show, fantastic, but please understand we may only stay a short time.
- **Keep Things Simple.** Please keep things simple, quiet and calm. Many of us are not able to multi-task anymore; we have to focus on one task at a time. Too much stimulation can intensify our symptoms.
- **Believe Us.** One of the most frustrating things is having people doubt our symptoms, because we "don't look sick". These symptoms are very real, trust in that.
- **Be Patient,** flexible and open-minded.
- **Have Empathy, Not Sympathy.** Brene' Brown explains it perfectly in this short [video](#).

DON'TS

- **Give Advice.** We have most likely searched all our symptoms and diagnoses on the web, both conventional and holistic. If we thought it would help us we would most definitely be doing it or have done it. If we want advice, don't worry we will absolutely ask you for it.
- **Minimize or Compare Our Symptoms.** Most of our symptoms are chronic but vary in intensity from moment to moment. Everyone is different and their symptoms will be different to. What works for one person may not work for another.
- **Get Upset or Take It Personally** if we have to cancel at the last minute. Just expect it and if we are



able to show we will. We realize this is asking a lot - but letting others down seems to be something we have to do often and the added anxiety of worrying about hurting or disappointing family/friends adds unnecessary stress to our lives, which can in turn intensify our symptoms.

- **Disappear.** These can be very lonely disorders. Many friends and family disappear because they don't understand what's happening. The silence from friends can be deafening. Call, text, message through social media; say something to let us know you are thinking about us.
- **Be Afraid To Be Real.** Be who you were when we weren't ill. We miss our former selves; we don't want to miss you too. Let's laugh, let's cry, let's talk!

PLEASE UNDERSTAND

- **The Basics:** Symptoms range from mild to severe and vary from moment to moment. Every individual may have similar but different symptoms and at varying intensities.
- **We May Avoid Noisy Environments.** Many sufferers are hard of hearing, deaf or have a difficult time hearing, they may be noise sensitive, use hearing aids or simply don't do well in noisy environments.
- **This Is A Lonely Journey.** Much of our support is online in social networks.
- **Our Symptoms Are Unpredictable.**
- Even though we may "look good", we may be just holding it together.
- **Many things intensify our symptoms:** Stress, too much stimulation, weather, lack of rest, etc.
- We don't always look "sick" and we don't like to hear that we look "fine."
- **We are no longer the person we were.** We are mourning our former selves, as we aren't able to do many of the things we use to do. So yes, we will cry from time to time.

THINGS WE DO NOT LIKE HEARING

- "Oh snap out of it." If we could, we would.
- "But, you don't look sick." If only we felt as good as we looked most days. We push through the majority of the time.
- "It's all in your head." Well, yes and no. The symptoms are caused by a few issues in my vestibular system, which happens to be in my head, but no, I am not imagining them.
- "You just need some rest." Why yes we do, but it's not going to cure us.
- "At least....."
- "Have you tried the ___ diet?"
- "Have you tried exercise?"
- "I wish I could stay at home like you."
- "Really, you are still sick?"
- "You are only given what you can handle."
- "I know how you feel."
- "Oh it's just a migraine."