



FAMILY SUPPORT

A VSGN LEADERSHIP SERIES DISCUSSION

Nov. 3, 2016

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Topic: How can we involve family members in support groups?

1. Introductions:
 - a. Cynthia: VEDA ED and family member (mother has Meniere's).
 - b. David: patient; wife is his "caregiver." They care for each other; he tends to be more concerned for her welfare than his own.
 - c. Stacey: PT; has caregivers in her support group who want to know how they can support their patient/family member. Patients in her support group want to know how they can explain to their family members what they are going through.
 - d. Nathalie: PT; recently started a support group.
 - e. Ann: husband, Gerry, has a vestibular disorder due to gentamicin toxicity, and after that happened has had a cascade of other health problems. He was their primary financial earner, but is now on disability. He falls a lot, has cracked ribs due to falling, walks slowly, and has hearing loss and brain fog. He found the Wobblers support group online, which gave him validation. She would read chats from Wobblers, which gave her a better understanding of what he is going through - i.e. hearing from another patient, not your family member, reinforces your family member's experience.
2. Time commitment: several people pointed out that family members may invest a significant amount of time, either in caring for the patient and/or adjusting their schedule to accommodate the needs of the patient.
 - a. How can patients acknowledge this and give family members permission to take time for themselves?
3. Roles: sometimes roles change when a patient gets sick - e.g. David was the primary breadwinner and now his wife works; Brenda's husband had to learn how to be a caregiver. It can be helpful for patients and caregivers to communicate about their roles.

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- a. Encourage individual counseling so both parties can learn how to express their feelings and ask for what they need.
 - b. Don't talk in the midst of the storm - wait until emotions are not high, and your physical symptoms have subsided.
 - c. Sometimes a 3rd person - e.g. another family member - can help with communication.
 - d. Caregivers sometimes don't want to burden people with their complaints - form a support group for caregivers so they can vent, get validation, and share coping strategies?
 - i. Possibly an online/Facebook group? Need a caregiver to moderate.
4. Including family in a support group - what does it look like?
- a. Invite them to come and participate any time.
 - b. Invite them 1-2/year and center the conversation around the impacts of living with a vestibular patient.
 - c. Create separate groups for caregivers (during the same meeting time or at a different time).
 - d. Online/Facebook group for caregivers to interact with each other
5. Sue Tucker invited family members to her last support group meeting. Following is a summary:
- a. 17 attendees; 50/50 mix patients/family
 - b. Some of the experiences that were shared:
 - i. A family of four presented their experience of having a wife/mother with the vestibular disorder.
 - ii. The mother and the children expressed that this resulted in a greater sense of independence and maturity for the children and a gratitude for the experience.
 - iii. The mother shared some of the coping mechanisms she used in order to raise her children with this problem.
 - iv. The husband and wife discussed some of their communication mechanisms, e.g. when they get into arguments they cannot raise their voice as it increases symptoms for the person with the vestibular disorder.
 - v. One young family brought up the issue of having children with the situation of vestibular disorder.
 - vi. Another young family shared what it was like to have a newborn one month after having been diagnosed with a vestibular disorder.
 - vii. Caretakers may be afraid to leave the person with the vestibular disorder alone, though the patient may actually want some alone time.
6. Other topics that might be good to bring up between family members and patients:

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- a. How do you convince family members to attend a SG if they don't think it's about them, i.e. that it's all about the patient?
- b. Education for caregivers - e.g. vestibular.org/fsn
- c. How do you bring up self-care for caregivers?
- d. How do you make it comfortable for caregivers to say how they are feeling/how they are impacted by the patient's limitations?
- e. How do you create a safe space for patients and caregivers to discuss difficult subjects, like if a caregiver feels that the patient isn't doing all they can to get better, or the reverse, i.e. the patient feels like the caregiver is babysitting them?
- f. How can both the patient and the caregiver get their needs met?
- g. Talk about journaling as a way for caregivers to express and examine how they are feeling.

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