VEDA

### LOGISTICS OF LEADING A GROUP

### A VSGN LEADERSHIP DISCUSSION TOPIC

### Scheduling

- Frequency: Quarterly, then as attendance increases, consider every other
- month or monthly.
- Seasonality: Consider not meeting in the summer or in December around the
- holidays.
- Day of Week: Consider the day of the week (Tu, W, Th may be better days;
- weekends may be difficult due to other commitments.
- Time of Day: Consider the time of day-early evening to allow people to
- attend after work.
- Length: 1 1/2 hours to allow everyone time to contribute.

### Topics/Guest Speakers

- VeDA Resources: Use meeting outline/resource list provided in Dropbox
- Format: Consider alternating discussion meetings with guest speakers to keep interest.
- Topics: Related to vestibular/balance disorders, coping strategies, diagnosis/treatment.
- Possible guest speakers: PT, Audiologist, ENT, Neurologist, Dietician, Acupuncturist, Yoga instructor, Reiki provider, LCSW/psychologist, vision specialist
- Possible Topics: Tai Chi, relaxation techniques, invisible chronic illness, how to complete disability paperwork, how footwear affects your balance, dealing with the busy holidays, how to talk to family, friends and coworkers about your vestibular disorder, how to deal with weather/barometric pressure changes.

### Communicating with Support Group Members

- Welcome: Send a standard "welcome" email to all who inquire about the group. Create a template that can be copied and pasted. (See VEDA's sample welcome letter.)
- Collecting Contact Information: Use VeDA's sign in sheet and registration card to track attendance and collect contact information.
- If they check the box that says they want to sign up for VeDA's e-newsletter, send the information to VeDA.

### VESTIBULAR DISORDERS ASSOCIATION

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- Meeting Reminders: Send reminder emails to your group members one week before the meeting. Include the discussion topic so that people can decide if the meeting is of interest to them (this can boost attendance).
- Make sure to let VeDA know in advance of your meeting schedule and topic.
- Confidentiality: Let members know that you will not share their contact information with anyone without their permission. Create a policy regarding how you will/will not share the contact information of one group member with another group member.
- Cancellations: Let group members know how they can contact you to find out about meeting schedules and cancellations. Have a policy about inclement weather (i.e. will meetings be cancelled due to inclement weather, and if so, how will you notify attendees?).

### Advertising

- Local Paper: Run a free ad in the community section of your local paper before you form the group to gauge the interest. Once the group starts to meet, continue to advertise (for free) upcoming meetings in the newspaper.
- Fliers: Create a flier and distribute to senior centers, community bulletin boards, and medical professionals.
- See VSGN resources for a flier with fillable fields for your group's information.
- Medical Professionals: Write letters to ENTs, PTs, and other specialists in your area and include a simple flier that they can post in their waiting room or make available to patients with your contact information. Do this periodically so that they know your group is still active.

### Notes from our Meeting:

- Customize these guidelines based on the needs of your attendees.
- Stacey pointed out that a topic that was VERY popular for her support group was having an audiologist come and speak about tinnitus coping strategies and treatments.
- Another popular topic is the cognitive/psychological aspects of vestibular disorders.
- If you plan on having several guest speakers at one time (e.g. an ENT, a PT and a psychologist) you may want to reserve a larger room and ask for RSVPs.
- Doctors may feel uncomfortable speaking to a support group because they are afraid they will run into former patients.
- Set boundaries regarding communication with your support group attendees.
  - Ask them not to call you late at night or early in the morning.
  - Get a Google phone number and set it up so it does not ring through to your phone, i.e. it acts as a message machine.

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- Emphasize confidentiality at the beginning of each meeting. Remind people not to share what was said or the names of attendees with others, even if they know each other.
- Sue suggested giving a flier to your local pharmacist and posting the meetings on Meetup.com.
- Susan suggested bringing hats with bills in case you meet somewhere there are fluorescent lights.
- Susan asked about dealing with people who have profound hearing loss. Some suggestions included:
  - Remind group members to speak clearly and loudly, and to face people with hearing loss when they are speaking.
  - Suggest that those people get personal sound amplifiers that can be worn over the neck (here's an inexpensive example).

#### VESTIBULAR DISORDERS ASSOCIATION