



## Support Group Leader Training – Section 4 – Resource 5

### Subject: What is the Purpose of Support Groups

#### Two Purposes of Support Groups

Support groups have two purposes: connection and information. Consider concentrating on speakers from your local area. Speakers work best when they highlight local resources for people from the same geographic area.

There are many recorded information sessions by nationally known speakers available on various TN websites. Thus, there is little to no need to invite nationally known speakers. In addition, it is more worthwhile to reserve their time for webinars and conferences, and many of their previous presentations are available on the TNAA website.

Connection is harder to come by, so the more leaders can create connection, the better. Think of ways to decrease isolation for support group members. Decreasing isolation is just as, if not more, important than providing information.

#### Starting a New Support Group

Meet with the TNAA SGL Co-ordinator to work out a strategy to promote your group, gather members, and move forward with next steps.

TNAA will promote your meeting to potential members. Promotion from TNAA can include: listing on the website, promoting on social media, promoting in the Quarterly Newsletter, sending an email blast to anyone in the TNAA database within a designated radius, or by identified interest. TNAA promotions will begin a minimum of 30 days out from your first meeting.

You may already have one or more people in your community in mind who can serve as the nucleus of your group. Or, someone willing to serve as a co-leader. You may find your members by talking it up among your facial pain buddies and their loved ones

You will be the point of contact for all potential members. If you are starting a local group, it will be up to you to provide the details of your meetings to participants. If you are leading an TNAA Virtual group, then TNAA will create an Eventbrite registration form that will include a Zoom

invitation in the confirmation email. TNAA will send you the list of participants at least two days before your meeting.

### **Scheduling Your Meetings**

For your first meeting decide on a meeting day and time convenient for you or based on availability of meeting space. You can always adjust later. For subsequent meetings, ask your attendees for input on convenient days and times for them.

Schedule your meetings at least 30 days ahead of time. Inform TNAA as soon as you schedule to give us enough time to promote and support your effort and you can provide a meeting date schedule if a regular time/date slot is agreed

### **Finding a Meeting Space**

Support Groups should be held in easily accessible, free meeting spaces. Options will vary from location to location. However, you are encouraged to start your search with:

- Hospitals
- Other healthcare facilities
- Community centres
- Meeting rooms or common areas in residential subdivisions
- Meeting rooms in county or city recreation facilities
- Libraries
- Worship centres

### **Note on meeting in healthcare facilities:**

Meeting in a healthcare facility can provide ample resources and central locations. However, please make sure you are not restricted to speakers and practitioners from that facility. Restricting speakers and topics is not consistent with FPA's education and support philosophy. In addition, you should have the option to provide a variety of speakers and topics for your group.

### **Topic Suggestions**

- Healing, Power of Friendship
- Deciding on Surgery
- What to expect before and after surgery
- A Partner's Perspective
- Coping Skills and managing Stress
- Returning Pain
- Medical Cannabis
- Surviving the Holidays
- Tips and tricks for avoiding triggers
- What to tell your children
- Dealing with feeling guilty
- Distraction projects
- Road to a diagnosis
- What to do with a new diagnosis
- How to handle an Emergency Room visit
- Masks and other facial coverings

- Coping with difficulty eating, shaving, brushing teeth, etc.
- Weight gain and facial pain
- Coping with the fear of pain and what is to come.
- Marriage and facial pain
- Intimacy and TN/ facial pain
- Integrative health/Complementary and alternative treatments • What have you learned because you have facial pain?
- Who have you been able to impact in a positive way through your journey?

### **Speaker Suggestions**

- Acupuncturist
- Chiropractor, Upper Cervical Care
- Dentists: Oral Surgeon
- Oral Facial Pain Specialist
- General Family Practice
- Gamma Knife Nurse
- Homeopathic Health Practitioner
- Internal Medicine
- Motivational Speaker
- Naturopathic Health Practitioner
- Neurologist
- Neurosurgeons who specialize in cranial nerve disorders and have experience with surgical treatments such as:
  - o Microvascular Decompression (MVD)
  - o Gamma Knife (GK)
  - o Percutaneous Procedures – Balloon Compression, Radiofrequency, or Glycerol Injection
- Neurosurgery Nurse
- Nutritionist
- Pain Management Specialist
- Partner or Spouse
- Pharmacist
- Psychologist
- Successful Surgery Patients/Panel

### **Ice Breaker Topics and Activities**

- What layers of pain management everyone uses
- Share one fact not related to facial pain
- Who has been most supportive in helping me to cope with the problems that facial pain has caused in my life? How?
- Who has been the least supportive? In what way?
- What did I used to think about people who had a form of neuralgia before diagnosis?
- Who is the easiest person to talk to about my face pain? Why?
- Who is the most difficult person to talk to about my face pain? Why?
- Do I really feel that I have a good rapport with my doctor?
- Am I open in expressing my symptoms and feelings with my doctor?
- How do people react to me when they learn that I have face pain?

- What problems related specifically to face pain have I overcome?
- What problems have I not succeeded in dealing with and why not?
- How has face pain changed my life and the lives of those I care about?
- What reactions to medications have people experienced?
- How do different people cope with pain differently?
- What surgical experiences have participants had?
- Talk about the constant quest to secure more information on the medical and surgical treatments available.

### **Finding a speaker**

The TNAA is a non-profit organization that does not offer compensation or travel expenses to speakers. However, many healthcare professionals and community members are willing to donate their time and expertise to help those living with facial pain, their families and loved ones.

### **Here are a few tips when approaching a speaker:**

*Don't be afraid to ask*

- Anticipate having to coordinate the scheduling with an assistant or practice manager
- Introduce yourself as a volunteer Support Group Leader with the TNAA
- Be realistic about the number of people in the group who will attend
- Accurately represent the time commitment for a speaker
- Give a potential speaker enough time to respond
- Make sure to confirm date, time, place, or Zoom meeting invitation
- Offer to have them speak by Zoom
- Ask for a specific topic or ask them to suggest a topic
- Ask if they have a website, head shot, and short biography, or anything they would like you to use when promoting their attendance
- Don't be afraid to ask for a commitment by a certain date
- Follow up by email to confirm once you have a commitment
- Re-confirm by email or phone several days to a week before your meeting

### **Pre-Meeting Preparation**

Confirm your meeting with all those who have expressed an interest in attending, and or to your usual list of members. Get in the habit of using the bcc (bcc) function of your email. There is no need to unintentionally share everyone's email address.

Providing name tags, if meeting in person, is a good way for everyone to break the ice. Encourage everyone in a Zoom meeting to provide a name. Or, ask if you can change their screen name.

Provide Sign-In Sheets for new members or members you don't have contact information for.

Provide hard copies of TNAA materials or a business card with relevant website addresses and links. If meeting by Zoom, have the TNAA website handy to link to in the chat box.

### Suggested Agenda

Meetings are generally scheduled for 1.5 to 2 hours. However, there may be times when you wrap up early and other times participants may want to visit with each other for longer.

You or your group may experiment with a meeting format to find one that works best for you. Here is a suggested agenda:

- Call to Order
- Introduce yourself
- Make any FPA announcements as provided
- Make any group related announcements or share any housekeeping details \
- Use an ice breaker, or provide a structure to keep things on track
- Introduce a speaker as appropriate
- Q and A Session with speaker as appropriate
- Group networking or social time
- Adjourn

### Suggestions for Managing Group Discussions

- Set the tone for the meeting by staying upbeat yourself.
- Encourage participants to present their own topics of concern for general discussion.
- Ensure that everyone has the opportunity to speak and to be part of the group discussion.
- Focus on what we can do, rather than on the failures of medicine or individual practitioners.
- Avoid meetings that degenerate into a “**pity party**” or a session of “**bash the doctor.**”
- Strike a balance between allowing people to vent and getting distracted from constructive goals.
- Remain neutral and unbiased. Listen to others’ concerns and/or difficulties.
- Share your personal experiences to increase awareness and educate members.
- Encourage your members to do their homework, gather information, contact TNAA Peer Mentor volunteers or keep attending Support Group meetings.
- Direct patients to the TNAA website for additional information.

### Managing Negative Group Member in Person

Dealing with negative members can be difficult, but it is very important to confront the situation before it destroys the group. One strategy for addressing the issue is to have the leader (or a designated group member) talk with the troubled person outside the group and try to determine circumstances that may be causing the adversity.

Negative group members are often chronic complainers, seeing not only the worst-case scenarios in their own lives, but often in the group as well. Their disagreeable and complaining behaviours run counter to the vital group dynamics of cohesion and safety.

This is not saying that occasional negative attitudes are not permitted. Living with a chronic illness, fear and chronic pain are all valid reasons for a person to feel discouraged at times.

The real problem is the chronically negative attitude and how contagious it can be if it is not dealt with rather quickly, the group can turn into a gripe session which is rarely, if ever, supportive or healing. Pessimistic members may get angry with the leader or with other

group members, may gossip and break confidentiality outside of meetings, or can be hostile or abusive.

If you are in the middle of conducting a discussion when a negative member begins to damage morale, try finding allies among the positive group members and encourage more participation from them, maintaining a constructive tone for the meeting. During this time, try to avoid eye contact with the negative member when asking questions of the group, so they do not have the opportunity to set a negative trend for the discussion.

It is generally not a good idea to confront the negative member directly in front of the group. This could very easily escalate into an argument or give the individual even more to complain about.

Try not to spend too much time focusing on a negative member, which can cause feelings of resentment and alienation in other members of the group. Keep in mind that a person's adversity is just a symptom of some unexpressed feeling.

The following solutions may be helpful:

- Paraphrase the participant's comments - be sure to emphasize relevant points, and afterwards their response, recap his/her position in objective terms.
- Ask the participant how their comments add value to the topic at hand.
- Find merit in the participant's comments - express agreement, then move on.
- Respond to the participant's comments, not the attack.
- Open a discussion of the participant's comments by soliciting for positive comments from the group.
- If time constraints are an issue - offer to discuss at next meeting or one-on-one, if necessary.

So long as drawing this person out does not consume most of the group time, it is perfectly appropriate to try to let him/her know that the group cares about how miserable they appear to be.

Attempt to reassure the individual that the group is concerned and interested in seeing this attitude and/or particular issue resolved, so that meetings can be productive and healing for everyone involved.

### **Managing a Disruptive Group Member on Zoom**

TNAA offers Virtual Support Groups open to all, and encourages locally based Support Group Leaders to invite those outside their geographic area to join virtual or hybrid groups.

The vast majority of participants will act as courteously in a virtual setting as they would in person. However, the ability to join a group on a drop-in basis where they feel semi-anonymous may lead some participants to be more negative or disruptive on Zoom than they would be in person.

To make virtual meetings as productive for everyone as possible, and to support our Leaders, TNAA recommends the following steps be taken if someone disrupts a virtual meeting.

1. Give them a chance to get in line and modify their behaviour
2. If behaviour continues, remove them from the meeting
3. Notify TNAA Committee of the issue as soon as possible
4. TNAA will decide if the person can continue to attend groups

**Send a Meeting Report to TNAA**

Complete a Meeting Report after each meeting. This ensures that new members receive an introduction to the TNAA via email with links to relevant information and added to the TNAA's ENEWS database to receive monthly tips to manage life with Trigeminal Neuralgia

**Keeping Track of Your Members**

Please keep track of your members along with their contact information. If possible, add new contact details to the SGL and Peer mentor contact form or use a spreadsheet that can be shared with TNAA on a periodic basis. Track the following information in the following format.

First Name, Last Name, Address, City, State, Postcode, Email, Phone

Do not hesitate to contact your SGL Coordinator for additional help in respect to any part of running your group

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*Excerpted from Bill Gareau, MHDL, in Group Counselling: Strategies and Skills, Jacobs, Harvil & Masson, Wadworth, Inc. 1988*

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*Please complete the Feedback Form – Support Groups - Section 4 Feedback 5 - before moving to the next training file*

*Credit to FPA Volunteer Handbook*