



Support Group Leader Training – Section 4 – Resource 4

Subject: What is a Peer Mentor

Peer Mentors are part of a support network for people who suffer from Trigeminal Neuralgia and related Facial Pain

They are volunteers who have been diagnosed with Trigeminal Neuralgia, who may or may not be currently pain free, are supported by Trigeminal Neuralgia Association Australia to provide assistance, empathy and understanding for any sufferer who needs someone to talk with

The role is not that of a certified trained counsellor, but one where the mentor is able to listen and provide information and support

What to Expect as a Peer Mentor

Peer Mentors may be contacted several times per month by sufferers from the Trigeminal Neuralgia community. As a Peer Mentor, you may sometimes interact with the same person several times, or speak to a different person each time. Whenever possible, follow the lead of the person contacting you and allow the number of interactions to come to a natural conclusion.

When you respond to an inquiry, you have the opportunity to lessen someone's isolation and increase their knowledge. Strive to remain neutral and unbiased. Listening to others' concerns and difficulties is the greatest kindness you can do for them. Do your best to provide encouragement and support.

Peer Mentors may share their personal experience in an effort to increase awareness and educate patients about their diagnosis and treatment experience. It is important to stress that every person and every situation is different, and as a result, treatments and outcomes can vary based on individual circumstances. Choosing the best treatment is a decision that must be made by both the patient and medical practitioner after careful review of the patient's case.

Encourage your contacts to do their homework when considering any treatment option. You may suggest they gather information, contact additional Peer Mentors, attend Support Group meetings or become members of Trigeminal Neuralgia Association Australia.

It's okay not to have all the answers. Contact other Peer Mentors or Support Group Leaders if you are ever in doubt about how to respond to someone from the facial pain community

Keeping Track of Your Contacts

It is important to keep track of how many people have contacted you, and the reasons, questions and information that is requested, in order to plan how many other resources are needed

Notes can be taken or you can enter the conversation points directly onto the website using the Peer Contact Form

Advice for Peer Mentors from Michele Cohen, LCSW Mentoring Members of the Facial Pain Community as an FPA Volunteer

Michele Cohen, LCSW is a New York City-based psychotherapist in private practice, with a special interest in videoconference support groups. Michele has facilitated a group for those living with facial pain since September, 2017. She also serves as a Support Group Leader with the FPA, and has formed a Support Group that meets weekly by Zoom. Prior to the formation of this group, she facilitated teleconference and videoconference groups for a variety of patients and caregivers coping with chronic illness.

Michele offered the following advice from her experience:

The most important aspect of being an Peer Mentor or Support Group Leader is to be present and actively listen to the person on the other end of the call or in a meeting. People living with neuropathic facial pain often feel quite alone and misunderstood - by friends, family and their medical team. Many have never had the opportunity to speak to someone who understands the condition-or to have a genuine conversation about their pain, be it physical, emotional or a combination of the two.

Having a genuine conversation is easier said than done for a variety of reasons. We generally look to solve problems by gathering facts and information, in hopes of seeking out the best possible course of treatment available. This is essential. In fact, if we didn't go this route, we would be foolhardy. However, there comes a point where factual information may fail to provide the help people are looking for. In addition, it's important to know that any mentor, even one who is a medical doctor or psychotherapist, is **not** working in their capacity as a professional in their role as mentor. Further, the role of mentor, by its nature, is limited.

Rather than hard and fast rules for answering questions, what I am proposing is general advice. Every one of us is different, and we all need different things at different times. Mentors can offer valuable advice because they have walked in the same shoes as their mentees.

My first piece of advice is not to take anything personally. It's hard not to experience feelings of frustration toward the person we wish to help. We are human, too!

Giving advice about treatment options and providers is pretty straightforward, but may or may not be appreciated - for reasons not readily understood. This gets even stickier when a mentee may try to destroy our capacity to help. The mentee may or may not be aware of their tendency to get in their own way when seeking out help for themselves.

They have little recognition of the effect they have on people, and frequently feel victimized rather than understood. Many are already angry and frustrated, and have no other way of communicating how they feel. While the majority of people who seek out help are grateful for it, we will at one time or another encounter situations in which we, as mentors, feel stepped on and unappreciated.

There may even be times, with particularly with a demanding mentee, when we may say hurtful things and feel badly about saying them. If that happens, it is important to take responsibility for our contribution to the impasse. A sincere apology can go a long way in helping someone begin to trust us a little more.

Second, just listen. Be present to bear witness.

Third, it's not your responsibility to fix what feels so broken. There will be times when the mentee may need more than we are capable of giving them. The question of offering a referral to a licensed mental health professional is a difficult question to answer. Many patients, particularly those who are emotionally brittle, may experience this kind of intervention as shameful and rejecting. Remember, that many have already heard the suggestion from family members and medical providers, and are reaching out to YOU and not to a licensed professional.

Fourth, protect your time. There are several ways to do this. Some people want to be helped "on demand". If you are comfortable with this model, this can be extremely helpful. However, most of us are not available in this way, and over time, will eventually feel some resentment toward the caller. This, in turn, will make it more difficult to listen empathically, and will interfere with your ability to help. I often tell people at the outset of the call how much time I have available, and stick to that time frame, even if the call is going well. It's important to be clear and consistent. Another suggestion is to find a mutually convenient time in advance, and to meet up then, with a clear sense of a time frame.

Fifth, don't try to DO anything. It's important to remember even though we know quite a bit about neuropathic facial pain, we know very little of what another person's experience is like. It's okay not to have answers. Knowing we don't have to provide "solutions" can be quite helpful and relieving to us.

Finally, I want to thank all of you for what you provide to help many of us who struggle with the effects of neuropathic facial pain.

Please complete the Feedback Form – Peer Mentor - Section 4 Feedback 4 - before moving to the next training file

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