

## From the website of Facial Pain Association:

### Frequently Asked Questions (FAQ) about Neuropathic Facial Pain and Trigeminal Neuralgia

See below for the most common questions asked of **The Facial Pain Association** (formerly *The Trigeminal Neuralgia Association*) about neuropathic facial pain, including TN (Trigeminal Neuralgia). The questions range from diagnosis to treatment options to how to talk to your doctor.

**Question:** *What is TN?*

**Answer:** Trigeminal neuralgia (TN) is a disorder of the 5th cranial nerve. TN causes sudden shock-like facial pains, typically near the nose, lips, eyes or ears. It is said to be the most excruciatingly painful human condition in the world. TNA's origin is unknown, but it is often attributed to abnormal blood vessels that compress the nerve, multiple sclerosis, or tumors. The disorder is named for the three-part (trigeminal) nerve that supplies sensations to all parts of the face.

**Question:** *What is the difference between TN and neuropathic facial pain (or atypical TN)?*

**Answer:** TN is characterized by jolting, stabbing, or electrocution-type pains, neuropathic facial pain is better described as constant, dull, burning or boring pain with intermittent sharp stabbing pains. Numbness and tingling may also be present with neuropathic facial pain.

**Question:** *I have never heard of TN, is it a relatively new disorder?*

**Answer:** TN was first described in medical literature as early as 1672. Some people know the disorder as Tic Douloureux. TN is often misdiagnosed as a toothache or TMJ. Many people go undiagnosed for years. Some people are misdiagnosed with TN although what they have is actually neuropathic facial pain.

**Question:** *What are some of the disorders often misdiagnosed as Classic TN?*

**Answer:** Sometimes injury to the end of the trigeminal nerve is caused by some type of trauma, such as a dental procedure or a blow to the face. Post herpetic neuralgia, better known as shingles, occurs after a herpetic breakout. The pain of neuropathic pain is usually constant, but can fluctuate in intensity. The pain is usually described as burning, aching or tightness. Many times numbness is present. This type of pain is difficult to treat and the procedures for classic TN can make this type of pain worse.

**Question:** *What causes TN and other types of facial pain?*

**Answer:** TN is often caused by loss of or damage to the nerve's protective coating, *myelin*, is usually involved. The most widely accepted view is that myelin damage results from irritation of the nerve, usually a blood vessel that causes the nerve to be compressed. Multiple sclerosis lesions and abnormal growths can also cause TN. Other types of facial pain can be caused by an outbreak of shingles or a similar virus or an injury to the nerve.

**Question:** *Isn't there a test of some sort of test to tell if you've got TN?*

**Answer:** No. TN is diagnosed almost exclusively by the individual's description of the symptoms. To rule out other sources of facial pain, doctors typically order a magnetic resonance imaging (MRI) scan when TN is suspected, but that's done to check for multiple

sclerosis or a tumor that might be causing the pain — not as a way to “see” if anything is irritating the trigeminal nerve.

**Question:** *Some people say their trigeminal or neuropathic pain started soon after dental work. Can that cause facial pain?*

**Answer:** The nerves that supply our teeth are the same as those that transmit TN and other types of facial pain. Some believe that the trigeminal nerve and its myelin sheath have already been damaged, and the pain is triggered by a dental procedure.

**Question:** *I am having difficulty at work because of my pain. Is TN or neuropathic facial pain a disability?*

**Answer:** Yes, both disorders are considered *impairments*, which can limit an individual’s ability to function on the job.

**Question:** *No one seems to understand the intensity of this pain. I feel so alone. What can I do?*

**Answer:** Some people are encouraged when they talk to others who have experienced facial pain. TNA has support networks, offering people the chance to share their experiences with one another. Counseling can sometimes help an individual to sort through the stress and isolation that can accompany facial pain.

**Question:** *Is medicine prescribed for TN?*

**Answer:** Yes, it is normally treated with anticonvulsants. Tegretol (carbamazepine) is often the most effective treatment. Some of the other medications that are commonly prescribed are Dilantin, Carbatrol, Trileptal, and Lyrica. If these medications become ineffective or the side-effects become intolerable, surgical treatment may be offered.

**Question:** *I just started on medication, and I am having difficulty concentrating? Will this side-effect go away?*

**Answer:** Some side effects may go away as your body adjusts to the medicine. Tell your healthcare provider if you have any side effects that continue or get worse.

**Question:** *Does TN ever go away on its own?*

**Answer:** Sometimes, but it’s not likely. TN pain typically runs in cycles, and it is common for individuals with TN to experience periods of remission. Remission can last for weeks, months, and even years. Over time, the attacks tend to worsen with fewer and shorter pain-free periods.

**Question:** *What are the surgical alternatives for TN?*

**Answer:** Several types of surgical procedures are available.

**Microvascular Decompression Surgery (MVD):** This procedure removes the cause of the TN pain. The MVD offers the best chance of long-term relief without damaging the nerve. The goal of the neurosurgeon is to lift the offending vessel from the trigeminal nerve by placing a padding between them. This procedure requires a craniotomy (surgical removal of a section of bone from the skull for the purpose of operating on the underlying tissues) and has the longest recovery time.

**Damaging the nerve:** Several procedures can be done to stop the transmission of pain signals to the brain. These procedures actually cause damage to the nerve and can be effective for varying lengths of time. Procedures that go through the cheek with a needle are glycerol injections, balloon compression, and rhizotomy (radiofrequency lesioning). They can be done in the X-ray suite or the operating room. Stereotactic radiosurgery uses highly

focused beams of radiation, causes a slow formation of a lesion in the nerve over a period of time to interrupt the pain transmission.

**Question:** *I have a consultation with a neurosurgeon. What should I ask him or her about a procedure?*

**Answer:** It is important to be informed about possible risks or side-effects and what to expect the first week or so after surgery. Some procedures may take months before the individual with facial pain notices the results, so you may want to ask your doctor how much time it will take to know if your procedure has helped your pain. Another important thing to ask is what the surgeon's success rates with this procedure are. You can follow up that question by asking what results the surgeon considers to be successful as well as unsuccessful. Sometimes people are concerned that their questions might sound stupid, but there are no stupid questions when it comes to something as important as a surgical procedure.

**Question:** *I have atypical facial pain, which has also been called neuropathic facial pain. What can be done for this type of pain?*

**Answer:** Medications sometimes help control neuropathic facial pain. People with neuropathic facial pain may be prescribed anticonvulsants such as Lyrica or Neurontin. Anti-depressants, such as Elavil or Cymbalta, can also help with the pain. Complementary Alternative Medical (CAM) treatments can also be helpful.

**Question:** *I have neuropathic facial pain, and medications have not helped. What else can I do?*

**Answer:** Many people find that complementary alternative medical (CAM) treatments can bring some relief. These therapies include things like upper cervical chiropractic (UCC), acupuncture, herbal remedies and vitamins, special diets, and neurostimulation.

**Question:** *Will CAM work for people who have classic trigeminal neuralgia?*

**Answer:** Sometimes we hear that CAM treatments have helped relieve TN pain. What we have learned is that therapies that help one person may not offer relief for someone else.