

# PATIENT GUIDE

UNDERSTANDING  
NEUROPATHIC  
FACIAL PAIN



**FacialPain**  
Association

# Welcome to the Facial Pain Association

There are more than 4.3 million people in the United States afflicted by nerve-generated facial pain. The Facial Pain Association (FPA) is a 501(c)3 national nonprofit organization founded in 1990. Since that time, FPA has evolved into the world's largest organization providing support, education, and advocacy for people affected by neuropathic facial pain.

*The mission of FPA is to serve those with neuropathic facial pain, including trigeminal neuralgia, through support, education, and advocacy.*

You have found the right place whether you are newly diagnosed, researching treatment options, or seeking additional information about ways to cope, connect, and get support.



# FPA Can Help

**FacePain.org** includes the latest information about diagnosis, symptoms, treatment options, pain management, medication, mental health, doctor, and medical center information. Our website houses a library of educational webinars, medical articles, and links to a variety of additional helpful resources.

**FPA Support Groups and Peer Mentors** provide local contacts throughout the United States, as well as a web-based interactive community of people with facial pain from around the globe.

**Webinars, Quarterly journals, and Bulletin updates** provide ongoing information from top medical professionals, event notifications, research updates, and more.

**The FPA Young Patients Committee (YPC)** recognizes the unique issues faced by people under age 40. YPC gives a voice to younger patients and raises awareness that neuropathic facial pain does not only affect older adults.

**Social Media** - FPA maintains an active Facebook Page, Facebook Group, and accounts on Twitter, Instagram, and LinkedIn. YPC also has a Facebook Page and Instagram account. Links can be viewed on the back cover of this Patient Guide.

We hope you find this Patient Guide to be a valuable tool for understanding your diagnosis and helping you to determine your treatment plan. We encourage you to become an educated patient or caregiver. It is important to understand your options, connect with a network of support, and learn to manage facial pain so it does not manage you.

# What Is Facial Pain?

## Types of Pain

The sensation of pain involves communication between your nerves, spinal cord, and brain. There are different types of pain, depending on the underlying cause.

### Acute or Chronic

Acute pain comes on suddenly, is usually sharp in quality, and has a specific cause. It serves as a warning of disease or a threat to the body. Acute pain will go away when the underlying cause is treated. Examples of acute pain are cuts, burns, bone breaks, and childbirth.

Chronic pain lasts for many months or years, and is not eliminated after an underlying problem is fixed. Chronic pain can be difficult to treat and may require trying various therapies to reduce the pain. The source of ongoing pain can be nociceptive or neuropathic.

### Nociceptive or Neuropathic

Nociceptors, pain receptors for tissue injury, exist throughout your body. Nociceptive pain occurs when damage is inflicted on body tissue, often an external injury such as stubbing your toe or getting injured during sports. Nociceptive pain can be acute or chronic.

Neuropathic pain is caused by damage or injury of the nervous system, affecting 7-10% of the general population. This type of pain can occur without an obvious cause. The symptoms of chronic neuropathic pain can be complex, making treatment decisions difficult.



## Neuropathies Defined

Neuralgia refers to pain in the part of the body served by a nerve or group of nerves. Nerves can be affected by pressure, heat or cold, or chemical means—and this can cause pain. This pain is called a neuralgia. The neuralgia can be continuous or on-and-off and is characterized by terms such as stabbing, shooting, or sometimes constant burning or tingling. Pain is felt along the route of the nerve in the body.

The term *neuropathic* means there is a lesion or disease within the neural system. The “pathic” part of the word tells us that there’s an abnormality, including injury, tumor, or disease as a causal factor. Neuropathic pains can be sub-classified even further based on their location as being either central (located in the brain/spinal cord) or peripheral (outside the brain). A neuropathy is basically thought of as a disturbance in function or pathological change in a nerve.

### Facial pain that is not neuropathic

Sometimes, the pain a person experiences is not trigeminal neuropathic pain; rather, the pain stems from other sources, including:

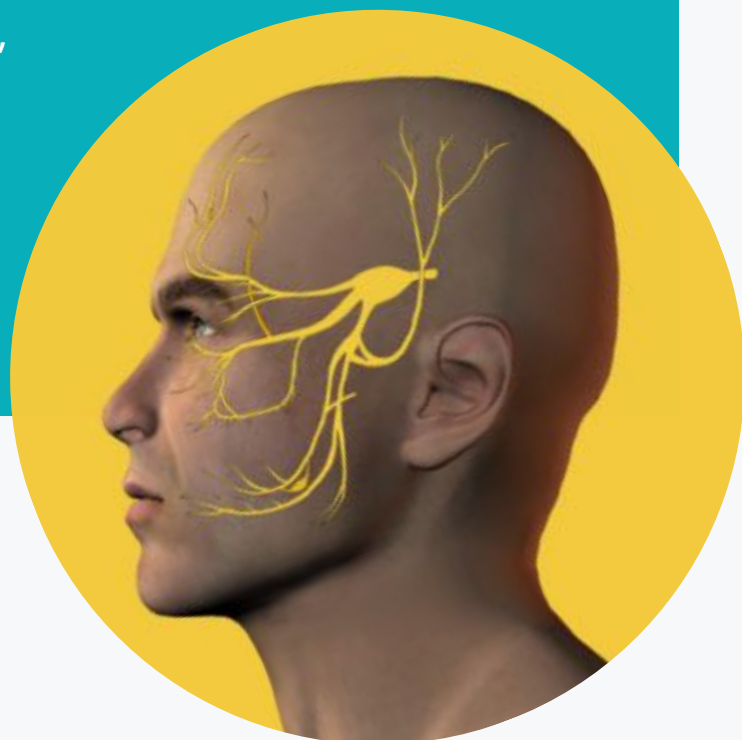
- Dental disease: cavities or gum disease
- Cracked teeth
- TMJ disorders
- Infections, including sinusitis
- Migraine headache
- Immunologic conditions: including multiple sclerosis (MS), Sjogren’s syndrome, and lupus
- Lyme disease

# The Trigeminal Nerve

To learn about neuropathic facial pain, it helps to know a little about how the affected nerves are laid out. There are 12 pairs of cranial nerves that can be seen on the surface of the brain. The trigeminal nerves are among these pairs providing sensations to your face.

The trigeminal nerve is the 5th cranial nerve, supplying sensation to the face, eyes, nose, lips, teeth, gums, part of the tongue, and part of the scalp. There are two trigeminal nerves, one on each side of the face. The trigeminal nerve is the largest and most complex of the 12 cranial nerves. Each side contains three branches, or divisions. You may experience pain in one or more of the areas of your face, head, and neck, depending on which nerves are affected. Each trigeminal nerve splits into three branches, controlling the feeling for different parts of your face:

- ophthalmic branch controls your eye, upper eyelid, and forehead
- maxillary branch affects your lower eyelid, cheek, nostril, upper lip, and upper gum
- mandibular branch runs your jaw, lower lip, lower gum, and some muscles you use for biting and chewing





# Diagnosis

Getting the correct diagnosis for your facial pain is the critical first step towards understanding your condition and receiving proper treatment.

## Three Steps to Diagnosis

An orofacial pain evaluation should consist of the following steps:

**History:** Perhaps the most important step in the diagnostic process is history taking, which leads the clinician to develop an initial differential diagnosis. By talking to the patient and collecting the right information, the clinician narrows down the list of all the possible conditions to a few more likely ones. For example, knowing the patient's age and gender already provides a good pointer towards conditions that may be more or less frequent in that group.

**Physical examination:** After the history taking, the clinician should have generated a mental list of the possible conditions that could be causing the pain. The physical examination will serve to confirm or refute such hypotheses and guide the process of diagnosis. The trained professional may be able to gather further information beyond what is volunteered by the patient, starting from general appearance, affect, posture, gait, speech, and non-verbal communication.

**Diagnostic testing:** No tests or exams are able to objectively confirm the source or even the presence of pain. In most cases, comprehensive history and examination will reach a diagnosis; however, there are clinical findings that require further investigation of the causes of specific signs or symptoms, especially to rule out disease or pathology underlying these features. An MRI (magnetic resonance imaging) scan is a primary diagnostic tool for facial pain diagnosis. MRI uses a large magnet, pulsed radiofrequency waves (RF), and an analyzing computer to create an image of the brain. The scanner itself is a tube with a table in the middle, into which the patient slides for a 45-minute session.



# Trigeminal Neuralgia

Trigeminal neuralgia (TN) is a neurological pain in the trigeminal nerve. TN is most often caused by a blood vessel compressing and injuring the nerve. TN episodes may start as short, mild attacks and progress to cause longer, more-frequent bouts of searing pain. TN pain is described as sudden, intense, "stabbing" or "shock-like". This pain can occur almost anywhere between the jaw and forehead, including inside the mouth. This pain usually occurs only on one side of the face, and can include facial twitching.

A constant aching, burning feeling may also occur before evolving into the spasm-like pain. Many people report that their TN attacks become more intense and frequent over time, sometimes with pain-free periods in between.





# International Headache Society - Classifications of TN

## **IHS classifications of TN**

The diagnostic classification of classical trigeminal neuralgia from the 3rd edition of The International Classification of Headache Disorders, devised by the International Headache Society, provides one recognized set of TN diagnosis criteria:

### **Classical trigeminal neuralgia (also called TN1/Typical TN)**

Description: Classical trigeminal neuralgia without persistent background facial pain.

### **Classical TN with concomitant continuous pain (also called Atypical TN/ATN/TN 2)**

Description: Classical trigeminal neuralgia with persistent background facial pain.

### **Secondary trigeminal neuralgia**

Description: Trigeminal neuralgia caused by an underlying disease.

### **Idiopathic trigeminal neuralgia**

Description: Trigeminal neuralgia with neither electrophysiological tests nor MRI showing significant abnormalities.

### **Painful trigeminal neuropathy**

Description: Facial pain in the distribution(s) of one or more branches of the trigeminal nerve caused by another disorder and indicative of neural damage (including herpes zoster, postherpetic neuralgia, and post-traumatic neuropathy).



# Causes of Pain

## Pain triggers

Stimulus-provoked pain is typical of TN. Triggered pain is one of the signs to your doctor to indicate a diagnosis of TN. In most people, TN pain is triggered by 'innocuous mechanical stimuli' that would not hurt someone without TN. Subtle stimuli can be a breeze or light touch of the face. Touch plus facial movements can also trigger pain. Movement alone can also be enough to provoke TN pain. The location of your pain may be different from the location that was stimulated. You may also experience a refractory period of several seconds or minutes after a pain attack when a new attack cannot be provoked.

## Anesthesia dolorosa

Anesthesia dolorosa (AD) is a feeling of pain in an area that is completely numb to the touch. "Anesthesia dolorosa" literally means "painful numbness". Numbness describes a loss of sensation or feeling in a part of your body, but it is often accompanied by or combined with other changes in sensation. AD causes pain in one or more areas of the face which are completely numb to touch. The pain is described as constant, burning, aching, squeezing, heaviness, tightness, pressure, or likened to pins and needles. The primary pain is usually continuous or near-continuous. You may also experience brief bursts of pain, but these are not typically the predominant pain type. Diagnosis is generally based on the description of symptoms.



## **Geniculate neuralgia**

Geniculate neuralgia is a rare type of nerve pain that occurs when a branch of the facial nerve, the nervus intermedius, becomes damaged or compressed. Ear pain, ranging from mild to debilitating, is one of the most common symptoms.

Geniculate neuralgia results in severe, deep ear pain which is usually sharp—often described as an "ice pick in the ear"—but may also be dull and burning. Ear pain can be triggered by stimulation of the ear canal, or can follow swallowing or talking, and can be accompanied by other facial pain.

Treatment for geniculate neuralgia usually involves managing symptoms with medication and noninvasive therapies. In severe cases, surgery may be recommended to decompress the facial nerve.



## **Glossopharyngeal neuralgia**

Glossopharyngeal neuralgia (GPN) is a condition causing throat, ear, and neck pain. The characteristics of GPN are similar to trigeminal neuralgia with some differences, which must be identified for the correct diagnosis and treatment. Clusters of unilateral attacks of sharp, stabbing, and shooting pain localized in the throat, radiating to the ear or vice versa, are characteristic of GPN.

## **Occipital neuralgia**

Occipital neuralgia (ON) is a condition in which the occipital nerves that run through the scalp are injured or inflamed. This causes headaches that feel like severe piercing, throbbing, or shock-like pain in the upper neck, back of the head, or behind the ears. It is not uncommon in a facial pain practice or in a headache clinic to hear from patients about pain in their face and head that originates, focuses, or culminates in the back of the head, the region that is called occiput. The patient's description of the pain location may – and usually does – help in making a correct diagnosis as most nerves in the head and neck region cover very specific anatomical distributions.

## **Postherpetic neuralgia**

After a patient has had chickenpox, the virus lies inactive in nerve tissue near your spinal cord and brain. Years later, the virus may reactivate as shingles. Postherpetic neuralgia (PHN) is the most common complication of shingles. PHN is pain resulting from a herpes zoster outbreak (shingles) along the trigeminal nerve. Postherpetic neuralgia occurs if nerve fibers are damaged during an outbreak of shingles. Damaged fibers can't send messages from the skin to the brain as they normally do. Instead, the messages become confused and exaggerated, causing chronic pain. The most common area to have PHN is along the torso, but pain in the face can also occur. The sensation may be of intense burning or stabbing, and it may feel as if it is shooting along the course of the affected nerve.

PHN typically starts during the shingles outbreak, but lasts after the rash and blisters have healed. Chickenpox causes shingles later in life. People over the age of 60 have an increased risk of shingles. Treatment for PHN does not cure it, but aims to minimize its symptoms.

## **TMJ disorders**

The temporomandibular joint (TMJ) acts like a sliding hinge, connecting the jawbone to the skull. There is one joint on each side of the jaw. Pain in the temporomandibular joint may occur in 10 percent of the population and Temporomandibular Disorders (TMD) have been reported in 46.1 percent of the US population. Inflammation within the joint accounts for TMD pain.

Common factors for TMD include bruxism (teeth grinding), trauma, bite abnormalities, and emotional stressors. Chronic joint disorders are more frequently associated with painful derangement of the TMJ. Management of TMD is usually achieved with reducing stress on the joint through exercises and splint therapy, coupled with medications such as anti-inflammatories and muscle relaxants.

## **Other causes of neuropathic facial pain**

You can read more about additional causes of facial pain on our website at [www.FacePain.org](http://www.FacePain.org).





# Misdiagnosis of Facial Pain

Symptoms related to facial pain can be complex. They may not fall into any one specific category. Some people with neuropathic facial pain are misdiagnosed as having dental or other issues. Until you have an accurate diagnosis, you may be getting unnecessary and even harmful treatment, and the cause of pain is not being addressed.

## **Will facial pain go away on its own?**

Sometimes, but it is not likely. Neuropathic facial pain does not usually go away completely. Some facial pain runs in cycles with periods of remission lasting weeks, months, and even years.





# Treatment of Neuropathic Facial Pain

## Medication

Once you and your doctor have determined the appropriate diagnosis, medication will usually be the first line of treatment. Anticonvulsant medications, which slow down the nerve's conduction of pain signals, will most likely be prescribed first.

For trigeminal neuralgia, carbamazepine is often the most effective treatment. Initial pain relief with carbamazepine is so common that many physicians consider positive results from its use as a means to confirm TN as a diagnosis. The medication is introduced slowly and levels increased until the patient is pain-free or negative side effects occur.

Most medications used for trigeminal neuropathic pain are used off-label, or prescribed by a doctor for a different purpose than originally approved by the Food and Drug Administration (FDA). Oftentimes, people with neuropathic facial pain try combinations of medications and increase or decrease doses over time in attempts to find what works for them.



## Medications

Anticonvulsant medications that may help stop seizures are prescribed because they can also stop pain being felt within the body. Antidepressants may be prescribed, not because you may be depressed, but because they can control pain.

- Carbamazepine (Tegretol), oxcarbazepine (Trileptal), Phenytoin (Dilantin, Phenytek), gabapentin (Neurontin, Gralise), lamotrigine (Lamictal), other drugs, including clonazepam (Klonopin) and lacosamide
- Antidepressants: Tricyclic antidepressants: (Amitriptyline)
- Antispasmodic agents: Muscle-relaxing agents such as baclofen (Gablofen, Lioresal) may be used alone or in combination with carbamazepine.
- Opioids are helpful in some cases of pain.



# Managing Medications

Make sure to advise your healthcare professional of any medications or supplements that you are taking. Adverse drug events are linked to polypharmacy (the simultaneous use of multiple drugs). If you require opioid medications, the prescribing physician should consider the potential for metabolic drug-to-drug interactions which can cause serious adverse reactions that can be fatal.

If the anticonvulsant you are using begins to lose effectiveness, your doctor may increase the dose or switch to another type. Side effects of anticonvulsants may include dizziness, confusion, drowsiness, and nausea. Also, carbamazepine can trigger a serious drug reaction in some people, mainly those of Asian descent.

During all phases of medical treatment, patients must communicate their pain level and/or drug side effects to their healthcare provider so that medications can be regulated effectively.



# Surgical Treatments

## **Non-ablative (non-nerve damaging) treatment**

Microvascular decompression surgery (MVD) was designed to cause no additional nerve damage and offers the best chance of long-term relief. The surgeon enters the brain at the base of the skull and relieves the compression. The nerve is wrapped in a Teflon-like material and the opening to the skull is closed.

## **Ablative (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 (percutaneous) include glycerol injection, balloon compression, and radiofrequency lesioning. These treatments can be done in the X-ray suite or operating room.





# Ablative Surgical Treatments

**Balloon compression** works by selectively injuring nerves which mediate light touch. The procedure is generally done on an out patient basis sometimes requiring an overnight hospital stay. The procedure is performed in an operating room under general anesthesia. Balloon compression is a percutaneous procedure where a cannula (a thin surgical tube) is inserted through a puncture in the cheek, and guided to a natural opening at the base of the skull. A soft catheter with a balloon tip is threaded through the cannula. The balloon is inflated squeezing the nerve against the edge of the dura and petrous bone.

**Glycerol injection** relieves pain by bathing the nerve ganglion to affect demyelinated nerve fibers. The procedure can be done on an outpatient basis but may require an overnight hospital stay. Glycerol injection is performed under intravenous sedation. A thin needle is introduced through a puncture in the cheek and guided through a natural opening in the base of the skull.

**Radiofrequency lesioning** uses electric current to intentionally destroy part of the nerve. Current is delivered from a needle passed through the cheek through a natural opening in the base of the skull. The procedure is usually done on an outpatient basis. Radiofrequency lesioning requires the patient to be alternately sedated and awakened to duplicate tingling in the affected area, and correctly position the needle and current.

**Radiotherapy or radiosurgery** (Gamma Knife, CyberKnife) uses radiation to slowly form a lesion on the nerve to disrupt transmission of pain signals to the brain. Pain relief may take several months to realize. Radiotherapy and radiosurgery are non-invasive procedures performed on a outpatient basis. Highly-focused beams of radiation are directed toward the area where the trigeminal nerve exits the brainstem. To insure accurate direction of radiation, procedures may require the use of a head frame to immobilize the head.



## Disclaimer - Surgical Treatment Options

There are risks with all surgical procedures including the possibility of recurring pain. There is a slight chance of numbness resulting from microvascular decompression (MVD). Some degree of numbness can be expected with other surgical procedures as well. The majority of those with TN may find relief with a combination of various medications and/or surgeries. A significant number of people have persistent facial pain from dental procedures, auto accidents, sports injuries, exposure to toxic chemicals, and other unknown causes. For those patients standard medical and surgical protocols are often inadequate.





## Determining a Treatment Plan

- Confirm your diagnosis.
- Choose a physician who has considerable experience in treating neuropathic facial pain.
- Choose a physician who will present all appropriate treatment options for your type of face pain and who will attempt to answer all of your questions.
- Consider your general health and ability to tolerate surgical stress.
- If surgery is an option, choose a surgeon who is experienced and skilled in the procedure.
- Choose a physician who is willing to work with you to make the best choice for you. Do not hesitate to seek a second or third opinion.



# Understanding the Risks

All treatments offer a set of benefits and risks. Your tolerance for risk will be different from others'. Ultimately, choosing a treatment option is a personal decision, not a medical one. Consider having a frank discussion with your partner, family, or other loved ones before deciding on a course of treatment for your facial pain. Ask yourself:

- Do I understand all my treatment options?
- Do I understand the risks of each option?
- Do I accept the particular risks of the procedure I am considering?
- Do I have reasonable expectations for post-treatment recovery including pain, returning to work, and other activities?
- Do I have reasonable expectations for how my pain will be changed by having this procedure?
- Do I want to talk to others who have had this procedure?
- Do I accept the outcome of numbness or chronic pain syndrome?
- If I choose not to have surgical treatment now, when will I reconsider?



## Other Treatments

**Motor cortex stimulation** is a surgical procedure that implants electrodes on the surface of the brain to control pain signals. Neuromodulation is used for neuropathic and deafferentation facial pain. This off-label procedure is not yet FDA approved. Motor cortex stimulation is less complex than deep brain stimulation that involves implanting a device deep inside the brain.



## Complementary Health Approaches

Many people find pain relief with therapies including: acupuncture, biofeedback, capsaicin, homeopathy, nutritional therapy, Electrical Nerve Stimulation, Transcutaneous Electrical Nerve Stimulation (TENS), upper cervical chiropractic (UCC), vitamin B-12 injections, vitamin therapy, Botox, Low Level Laser Therapy (LLLT), herbal remedies and vitamins, special diets, and neurostimulation.

**Acupuncture** improves the body's functions and promotes the natural self-healing process by stimulating specific anatomic sites--commonly referred to as acupuncture points, or acupoints. The most common method used to stimulate acupoints is the insertion of fine, sterile needles into the skin. Pressure, heat, or electrical stimulation may further enhance the effects. Other acupoint stimulation techniques include: manual massage, moxibustion or heat therapy, cupping, and the application of topical herbal medicines and ointments.

**Medical cannabis** shows promise for relief of chronic, neuropathic pain though the amount of relief varies from study to study. Overall, studies show that it offers low to moderate pain relief. Some studies show considerable pain relief, while others show none at all; medical cannabis relieved pain no matter where in the body the pain occurred. However, there has not been a study that focused specifically on orofacial pain. Cannabis, the plant, and cannabinoids (naturally occurring compounds in the plant) do not always significantly improve pain, but consistently improve sleep and quality of life.

**Chiropractic** for facial pain offers a natural supportive strategy that helps reduce the pressure on the nerve system at different key locations. The upper part of the spine is known as the upper cervical spine or the cranio-cervical junction. The upper neck is the most neurologically sensitive area of the spine, and when injured can cause a host of neurological side effects. The Upper Cervical Chiropractic technique is a specific chiropractic procedure that corrects the position of the top vertebrae of the spine, called the atlas. By correcting the tilt, shift or rotation of these vertebrae, the effects of many conditions can be minimized or eliminated completely.

More information about these and other Complementary Health Approaches can be found on our website: **[www.FacePain.org](http://www.FacePain.org)**.



# Facial Pain and Your Mental Health

Taking steps to care for your mental health is just as important as caring for your physical well-being. It is important to realize that factors related to your facial pain can have a big impact on your mental health. There may be tension in your relationships. You may withdraw from people, hobbies, and activities you used to enjoy. You may make major life decisions based on your life with facial pain.

There is a strong link between chronic pain and depression. Chronic pain affects your mental health, and depression affects your physical well-being. Symptoms of depression include pain, fatigue, appetite changes, and difficulty sleeping.

The affect of stress on the body is a major reason chronic pain and depression are interconnected. Stressful situations, including episodes of pain, cause a flood of stress hormones that produce physiological changes. Known as the "fight or flight reaction" it evolved as part of your body's defense system. Stress hormones cause your brain to send signals to your body preparing it to fight or flee from perceived danger. Normally, when the pain stops the stress hormones recede and your body returns to a relaxed state.

However, with chronic pain the fight or flight signals never turn off, leaving the nervous system in a constant state of high alert. Over time constant stress wears your body down and can lead to depression which can increase pain which can deepen depression. Unfortunately, your body's natural defense system can turn against you and lead to a negative cycle of pain and depression. Coping with your facial pain and managing stress can help you break the cycle and battle depression.

Remember you do have treatment options to target both pain and depression. You can find ways to live your best life that may include antidepressants, psychotherapy, and stress management techniques. We encourage you to connect with the FPA's caring community of support to help you cope with your facial pain.

FPA offers webinars, articles, and information on various mental health topics. We encourage you to visit our website and contact us with any questions.

## What to Expect at the Emergency Room

Hospital emergency room staff may be unfamiliar with TN and neuropathic facial pain. Whenever possible, before an ER visit, ask your doctor to contact the ER physician and advise them about your case. When you go, bring a brief record of your facial pain history including medications and allergies, name and contact information of your treating physician.

Emergency room treatments may include medications intended to control acute pain such as: morphine administered intravenously (IV) or by injection; opioids; Depacon by IV or as an injection applied to the trigger zone, dilantin by IV, or Cerebyx (fosphenytoin) by IV or injection. The use of Cerebyx can provide rapid temporary relief but may require an overnight stay to provide close monitoring of heart function and blood pressure.



Emergency



## Tips for Caregivers

Providing help and support for a loved one in pain is extremely challenging. Caregivers find themselves devoting their time and energy to meeting new challenges while trying to balance their own needs and responsibilities. Below are some ways you can be an effective caregiver:

- Educate yourself about neuropathic facial pain. This will help you better communicate with healthcare professionals about treatment and care.
- Be the medical advocate and record keeper: obtain copies of medical correspondence, test results, record of medications tried, dosages, length of time taken, and side effects.
- Take notes of calls or meetings with physicians, hospitals, and insurance providers.
- Keep an observation journal so you can deliver precise information to doctors. Include medical visits, conversations, questions and answers, and date entries.
- Help people to understand what neuropathic facial pain is and how it affects people who have it. Education is the best way to advocate for facial pain sufferers.
- Notice non-verbal pain cues that indicate pain and discomfort or the need to retreat.
- Take advantage of extended support systems; for example, FPA Support Groups and the FPA Facebook Group.
- Take care of your own physical and mental health needs. Be aware of your stress levels, take breaks, exercise, and talk to a friend.
- Ask for help. We all have our limitations; be aware of your strengths and abilities. When people offer to help, accept the offer.

## Young Patients Committee (YPC)

The Young Patients Committee (YPC) assists in fulfilling the mission of the Facial Pain Association by representing the interests of neuropathic facial pain patients under age 40.

Because trigeminal neuralgia is often considered a condition that affects older people, some of the issues that young people with facial pain face on a daily basis can differ from those of the older generation. The YPC was created to give a voice to younger patients and to address their specific needs.

For more information about YPC, visit the social media links on the back cover of this guide.

The YPC also participates in FPA conferences with forums designed specifically for young people, and publishes articles in every edition of the FPA Quarterly. In addition, YPC spearheads fundraising initiatives, raising funds through sales of facial pain-related merchandise, helping to raise awareness.



## For Adults Under 40

In addition to navigating a new aspect of your relationship with family, you may also have a spouse or partner, employer, and friends who may need information and guidance from you about your facial pain. Spouses/partners need to understand when and how to show affection and what your physical limitations are. Talk with them about side effects of medication and how they impact your life. Your partner can be a vital advocate for you at the doctor's office and during hospitalizations; he/she may also receive the brunt of your negative feelings and pain. Employers likely will not understand the disease; they will require education about it and what you need to deal with your facial pain at work. Know your rights as an employee and be clear about your needs with your employer.



# Frequently Asked Questions

**Q: I have never heard of trigeminal neuralgia. Is it a relatively new disorder?**

A: TN was first described in medical literature as early as 1672. Some people know the disorder as Tic douloureux. TN is a rare disease, affecting approximately 12 of 100,000 people; consequently, many people, including doctors, are not familiar with it.

**Q: I am having difficulty at work because of my pain. Is facial pain a disability?**

A: Yes, facial pain is considered an impairment, which can limit an individual's ability to function on the job. You and your employer can work together to find accommodations such as a later start time or telecommuting.

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

A: Sometimes, but it is 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.

**Q: I have a consultation with a neurosurgeon. What questions should I ask about a procedure?**

A: It is important to be informed about all possible risks and side effects, and what to expect the first week or so after surgery. Some procedures may take months before the results are noticeable, so ask your doctor how much time it will take to know if your procedure has helped your pain. Of the procedures you are considering, ask how many has the surgeon performed, and what is the success rate. Follow up that question by asking what results the surgeon considers to be successful as well as unsuccessful. With your physician, you can make a good decision about which procedure will be best for you.

**Q: Is there anything I can do to avoid common triggers?**

A: Do not become overtired. Get plenty of rest and ask for help from your doctor if you are not sleeping well.

Avoid cold wind and drastic changes in temperature. Wear a jacket with a hood or a scarf, even when making a quick trip to the mailbox. Do not let your body and face get cold. This only takes a minute to avoid, but once the pain is triggered it make take hours to become bearable again.

Avoid stress, which is a major pain trigger. It can be difficult to manage, but it is very important to reduce stress. Say “No” and ask for help when needed. Take time out of your day for relaxing activities. Read, listen to a book-on-tape, watch a movie, take a hot bath, light candles, play music. Ask your doctor about an antidepressant; it can make a big difference in how you cope.

Be aware of changes in barometric pressure. It is helpful to know how the upcoming weather may impact your week.

Most importantly, know your triggers and do your best to avoid them.



# DISCLAIMER

**Disclaimer:** This document is not intended to replace the relationship between the patient with facial pain and the doctor. Nor is this document making a recommendation on any specific treatment. The information in this document is intended to help the reader better understand facial pain and to help those with facial pain make better informed decisions about their health care needs.



point  
**Legal**  
law or  
perm







FacialPain  
Association



# We are here to support you on your journey.

We encourage you to connect with FPA's network of Support Groups, and one-on-one support through our Peer Mentors. Call the national office: we are available to answer your calls 9am-5pm Eastern time, or email us at [info@tna-support.org](mailto:info@tna-support.org) any time.

## FPA Support Groups

For many people with facial pain, a support group is one of the only places where they can connect with others who share their experience. A support group provides understanding, encouragement, and reassurance that will help you adjust to life changes brought on by facial pain. All FPA Support Group meetings are FREE and open to the public. Whether you are personally affected by facial pain, are a loved one, or a person under age 40, FPA has a group for you. Find a support group by visiting **FacePain.org** under the Find Support tab.

## FPA Peer Mentors

Get one-on-one peer support from someone affected by facial pain, just like you, who has experience and advice to share. Peer mentors are available for you to call, email, or video chat -they will be sympathetic listeners, connect you to resources, and will share their best facial pain tips. Making a personal connection provides you with vital support, encouragement, and information.

We encourage you to take advantage of this important resource. Contact us to find a peer match today, we'll help connect you with new friends who truly understand your facial pain experience.

Please contact Regina at **[rgore@tna-support.org](mailto:rgore@tna-support.org)**.



## Follow us on social media

FPA maintains a Facebook group at **FPA | Official Trigeminal Neuralgia Network** and an organizational page for updates about events, relevant articles, and information.



@facialpainassociation



@facialpainassoc



@facialpainassoc



Facial Pain Association



*You make it possible for the FPA to continue to serve those affected by neuropathic facial pain.*

*Your gifts enable us to provide support, education and information to thousands of people with facial pain and their loved ones.*

***Your journey was likely not a direct path, but you are not alone.***

Join FPA's Pathway Membership and support our mission to reach more people earlier on their path to accurate diagnosis and appropriate treatment.

Your donation of \$50 or more entitles you to an annual FPA Pathway Membership, including:

- Hard copy of the FPA Quarterly journal mailed to you
- Email Bulletin containing FPA program updates, resources, and relevant articles
- Recognition in the FPA Annual Report

## GIVE TODAY

### Donate Online

[FacePain.org/donate](https://FacePain.org/donate)

### Donate by Phone

Call us Monday-Friday between 9:00 am – 5:00 pm ET and we will happily take your donation information over the phone!

**(800) 923-3608 or**

**(352) 384-3600**

### Donate by Mail

Please mail your check, made out to  
The Facial Pain Association to:

**Facial Pain Association  
4600 SW 34th Street, #141592  
Gainesville, FL 32614**

FPA is committed to serving the neuropathic facial pain community and your support is crucial to our mission. To learn about all the ways you can support FPA, visit [FacePain.org](https://FacePain.org) today.





**FacialPain**  
Association

**The Facial Pain Association**  
4600 SW 34th Street, #141592  
Gainesville, FL 32614

**[www.FacePain.org](http://www.FacePain.org)**

**1-800-923-3608 or 1-352-384-3600**

Phone support business hours:  
M-F 9 am – 5 pm Eastern Time

Email: **[info@tna-support.org](mailto:info@tna-support.org)**

