TNA
The
Facial Pain
Association

WELCOME TO TNA!

TNA - The Facial Pain Association is pleased to fulfill your request for information about TN and related facial pain conditions.

Who We Are

TNA - The Facial Pain Association, a non-profit, tax exempt organization, was established in 1990 by founding President Claire Patterson and a board of directors comprised of TN patients and their families. Until then most TN patients suffered in isolation and fear, knowing very little about the disorder and its treatment.

The mission of TNA – The Facial Pain Association is to serve as an advocate for patients living with TN and related facial pain conditions by providing information, encouraging research and offering support. For more information visit us at www.tna-support.org.

We Are Here For You!

The information you received today is one of the many services available through TNA. Others include:

- Our new TNA Quarterly Magazine published 4 times a year
- Community-based Support Group meetings throughout the country
- Telephone Support Contact Network
- Informational mailings on patient-related issues
- Check our website at www.tna-support.org for Regional and National interactive and informative Conferences for patients and doctors
- The new interactive online community for TN and other neuropathic face pain patients can be found at www.fpa-support.ning.com
- TNA FACEBOOK page at www.facebook.com/facialpainassociation
- Patient Services is available via email at patientrep@tna-support.org or via phone at 1-800-923-3608 for further information

TNA services are available through the generosity of our patients.

Your voluntary, tax deductible contribution will help us continue to be a vital source of educational information, support and research for you and others affected by facial pain.

The enclosed information will help you become more knowledgeable about facial pain disorders and their treatment. Although it is not a means of self-diagnosis, it will assist you to explore the most current methods of treatment with your physician.

You can also learn more about TNA, our services and opportunities for greater involvement, by visiting our website at www.tna-support.org.

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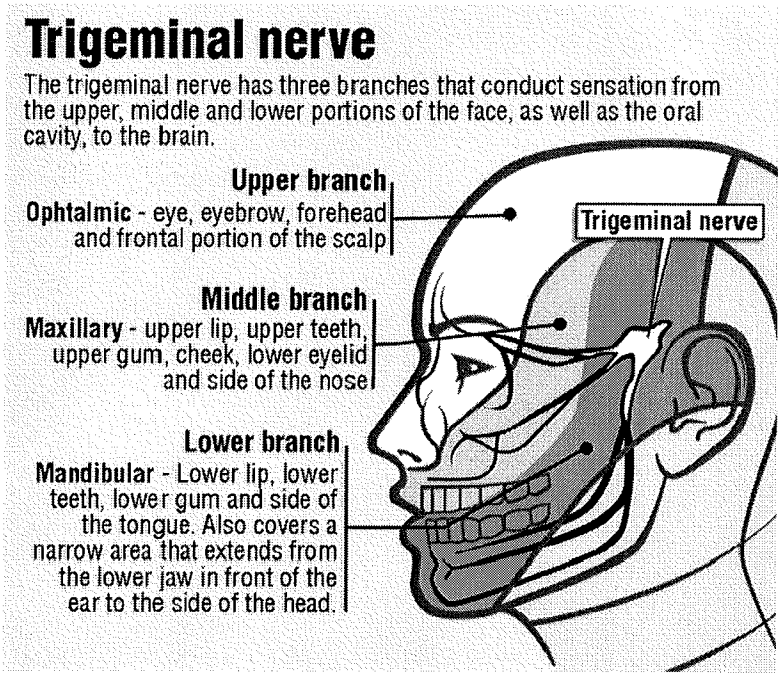
Understanding Neuropathic Facial Pain



The trigeminal nerve innervates a portion of the scalp, the face, nose, inside the nose, lips, inside the mouth, part of the tongue, and every tooth in the mouth. However, because the trigeminal nerve is involved does not establish the diagnosis as being TN. **There are many disorders that can affect the trigeminal nerve.**

Often it proves difficult for the physician and patient to determine the fine differences between classic trigeminal neuralgia and trauma induced trigeminal neuropathic pain. **In order to decide on the proper treatment plan it is imperative to recognize these differences.** A destructive procedure used for classic TN could make neuropathic pain much worse.

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Classification for Facial Pain

- **Classic Trigeminal Neuralgia, type 1, (TN1):** (also known as tic douloureux) facial pain of spontaneous onset with greater than 50% limited to the duration of an episode of pain (temporary pain).

- **Trigeminal Neuralgia, Type 2, (TN2):** facial pain of spontaneous onset with greater than 50% as a constant pain.

- **Secondary Symptomatic-Trigeminal Neuralgia (STN):** Pain resulting from multiple sclerosis.

- **Atypical Facial Pain (AFP):** facial pain of unknown origin.

- **Post- Herpetic Neuralgia (PHN):** pain resulting from trigeminal herpes zoster outbreak. (SHINGLES) Shingles, painful skin lesions caused by activation of Herpes Zoster (Varicella Zoster) virus, can occur along any nerve, including the trigeminal. If pain persists after the rash has gone away because of injury to the nerve, the condition is then called PHN.

- **Trigeminal Neuropathic Pain (TNP):** facial pain resulting from unintentional injury to the trigeminal system from facial trauma, oral surgery, ear, nose and throat (ENT) surgery, root injury from posterior fossa or skull base surgery, stroke, etc. This pain is described as dull, burning, or boring and is usually constant because the injured nerve spontaneously sends impulses to the brain. The injured nerve is also hypersensitive to stimulation, so attacks of sharp pain can also be present. The area which is sensitive to touch and triggers these sharp attacks is the same area where the pain occurs. Numbness and tingling are also signs of a damaged nerve.

- **Trigeminal Deafferentation Pain (TDP):** facial pain in a region of trigeminal numbness resulting from intentional injury to the trigeminal system from neurectomy, gangliolsys, rhizotomy, nucleotomy, tractotomy, or other denervating procedures. Despite the loss of sensation, constant pain is felt in the numb area(s), which varies in intensity and can include sensations of burning, crawling, tingling, boring, stinging, and/or unpleasant aching.

It is our hope that this classification scheme provides more accurate and precise communication among different specialist treating neuropathic pain.

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Treatment for Type 1, Type 2 and STN

There is a growing arsenal of ways to treat TN, including medications, surgical treatments and complementary and alternative medicine (CAM). To avoid any drug interactions, it is important to always advise your physician and pharmacist of all other drugs that you are taking, including over the counter medications, vitamins, minerals, and herbs.

Treatment with Medications

- Anticonvulsant medications, which slow down the nerve's conduction of pain signals, are usually the first treatment option. These include:
  - Tergretol
  - Trileptol
- Tegretol (carbamazepine) has been the primary drug used to treat TN. Many physicians believe that the relief of facial pain with Tegretol confirms the diagnosis of TN.
- Trileptal (oxcarbazepine) has recently been used more frequently as a first line drug for TN. It is structurally related to Tegretol, and may be preferable due to a more favorable side effect profile.
- Other medications that may be used in the treatment of TN and neuropathic facial pain include anticonvulsants like Dilantin, Lamictal, Keppra, Topamax, Neurontin, Klonopin and Lyrica.
- Antidepressants

During all phases of medical treatment, patients need to communicate their pain level and/or drug side effects to their health care professional, so that medication can be regulated effectively. These medications work best with a consistent blood level, so they must be taken on a regular schedule. To avoid serious side effects anticonvulsant dosages must be increased and decreased slowly as directed by your doctor. Do not stop taking these medications abruptly.
Switching medications may be necessary, so in order to maintain a pain-relieving blood level of medication, discuss with your doctor how to begin the new medication while tapering off of the old one.

Complementary and Alternative Medications (CAM)

As in traditional medical treatments, the effectiveness of all CAM treatments depends on several things, including the person's state of health, and the skill and knowledge of the practitioner. Every person responds differently to treatments, and even though most of these remedies are non-invasive, they still may have potential risk and complications.

- Acupuncture
- Biofeedback
- Capsaicin
- Homeopathy
- Nutritional therapy
- Electrical Nerve Stimulation
- TENS (Transcutaneous Electrical Nerve Stimulation)
- Upper cervical chiropractic
- Vitamin B-12 Injections
- Vitamin Therapy
- Botox
- LILT. Low Intensity Laser Therapy

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Surgical Treatments

PLEASE NOTE that the surgical treatments listed are for Trigeminal Neuralgia (TN1 and TN2) and Symptomatic Trigeminal Neuralgia (STN), caused from MS.

These surgical procedures are contraindicated for Related Facial Pain such as: Trigeminal Neuropathic Pain (TNP), Trigeminal Deafferentation pain (TDP), Post-herpetic Neuralgia (PHN) and Atypical Facial Pain (AFP).

- The Microvascular Decompression (MVD), which causes no additional nerve damage, is the most invasive of all surgical options to treat TN, but it also offers the lowest probability that the pain will return. This procedure requires a small opening be made behind the ear. While viewing the trigeminal nerve through a microscope, the surgeon places a soft cushion between the nerve and the offending blood vessels.

- Balloon Compression is an outpatient procedure, although sometimes the patient is kept overnight. It is performed in the operating room, with the patient receiving general anesthesia. In this percutaneous procedure, a cannula is inserted through a puncture in the cheek and guided to a natural opening in 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 the petrous bone. Balloon compression works by selectively injuring nerves which mediate light touch.

- Glycerol Injection is also an outpatient or overnight procedure. It is performed with intravenous sedation. A thin needle is introduced through a puncture in the cheek, next to the mouth and guided through a natural opening in the base of the skull. Just inside this opening is the trigeminal ganglion where all three nerves come together. Glycerol bathes the ganglion and affects the demyelinated fibers.

- Radiofrequency lesioning is usually performed in an outpatient setting. The patient is sedated for a few minutes while a needle is passed though the cheek, up thorough a natural opening in the base of the skull. The patient is awakened and a small electric current is passed through the needled causing tingling. When the needle is positioned so the tingling occurs in the same area of TN pain, the patient is sedated again and a radiofrequency current is passed through the needle to intentionally destroy part of the nerve.

- Radiosurgery (GammaKnife, CyberKnife, etc.) is a non-invasive procedure performed on an outpatient basis; it requires no incision but may require the attachment of a head frame. Highly focused beams of radiation are directed to the area where the trigeminal nerve exits
the brainstem. The radiation causes the slow formation of a lesion on the nerve that disrupts the transmission of pain signals to the brain. However, pain relief from this procedure may take several months.

With all of these surgical procedures, there is the possibility of TN returning. There is a slight chance of numbness with MVD, but some degree of numbness is expected in the other procedures.

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Treatment for Post Herpetic Neuralgia (PHN), Trigeminal Neuropathic Pain (TNP), Trigeminal Deafferentation Pain (TDP), Atypical Facial Pain (AFP) includes all medical and complementary and alternative medications.

This publication is intended to provide you with current information on TN/facial pain and possible modes of treatment. It does not constitute specific medical advice and should not be relied on as such without consultation with your physician.

Determining a plan of Treatment

- Choose a physician who has considerable experience in treating TN/Neuropathic facial pain
- Choose a physician who will present all treatment options that are appropriate for your type of face pain
- If surgery is an option choose a surgeon that is experienced with several different treatment modalities
- Willing to work with you – do not hesitate to seek a second or third opinion

Medical Resources

To find medical and dental professionals who are active in the treatment of neuropathic facial pain conditions, including trigeminal neuralgia, visit TNA's website at **www.tna-support.org**.

Patient Support

For direct, personal responses to your questions about TN and related facial pain, call 800-929-3608 or email patientinfo@tna-support.org. Patient information materials available from TNA include this patient information packet, a newsletter, a nationwide list of patient support groups and limited treatment referral resources.

Join TNA's efforts to end the pain

We know that you will find the enclosed information helpful and that you will want to become involved with TNA. Our ability to continue providing a high level of support can only occur through the generosity of those we serve. Your tax deductible contribution of any amount will help us achieve our stated mission and continue being a vital resource to you and others like you.