



Support Group Leader Training – Information

Subject: Help Sheet – A Diagnosis of Facial Pain

Getting the correct diagnosis for your facial pain is the critical first step towards understanding your condition and receiving proper treatment. The Office of Rare Diseases (ORD) of the National Institutes of Health (NIH) considers trigeminal neuralgia a rare disease. This is known as prevalence. The incidence of trigeminal neuralgia, or how many people are newly diagnosed each year, is thought to be 4.3 people per 100,000. Other neuropathic facial pain conditions are also rare. Some people have more than one type of pain, either concurrently (at the same time) or subsequently (one follows the other).

One reason for a poor treatment response is that the causative diagnosis was incorrect. ENT surgeons may diagnose a sinus condition when it is not present. Dentists may consider trigeminal neuropathic pain to be treatable by invasive dental surgery when it should not be. Differentiating between the various types of facial pains and mechanisms associated with neuropathies can sometimes be confusing, especially if the symptoms are complex and don't fall into any one specific category.

The American Medical Association estimates that primary care physicians might expect to encounter trigeminal neuralgia two to four times over the course of a 35-year career, and this is also true of medical professionals in Australia. Doctors and dentists have limited medical training on the topic. If you think your doctor does not know much about neuropathic facial pain, you may be right.

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, only to find that they have a neuropathy. Until you have an accurate diagnosis, you may be getting unnecessary and even harmful treatment, and the case of pain is not being addressed.

“Neuropathic” pain requires there to be the presence of a lesion or disease within the neural system. A *neuropathy* is a disturbance in function or pathological change in a nerve or nerves. Many facial pains mimic a neuropathy, so it is important that there is a systematic approach to determining an accurate diagnosis.

Classification of trigeminal neuralgia – why is it important?

Over the years, the terms used for trigeminal neuralgia have changed, and one doctor will apply these terms differently than another. The cause of classical TN is typically nerve compression by a vessel, usually the superior cerebellar artery on the trigeminal nerve root as it leaves the brain stem. However, in some cases, compressions may not be found. Your description of your pain may not match your diagnosis. You may have an underlying disease causing your pain. A large portion of patients have continuous pain between attacks.

Taking all of this into account, an experienced doctor will be able to help you understand your facial pain and provide you with a recommended treatment plan.

IHS Classifications of TN

The diagnostic classification of TN from the 3rd edition of The International Classification of Headache Disorders, devised by the International Headache Society, is based on reliable clinical data, imaging, and neurophysiologic studies. It reflects current knowledge and has improved the possibility for clinicians to choose adequate management options. The ICDH-3 classifications provide one internationally recognized set of TN diagnostic criteria:

1. Classical trigeminal neuralgia (also called TN1/Typical TN)

Description: Classical trigeminal neuralgia without persistent background facial pain.

2. Secondary trigeminal neuralgia

Description: Trigeminal neuralgia caused by an underlying disease.

3. Idiopathic trigeminal neuralgia

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

4. 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).

Where to find a facial pain diagnosis

How can you find a healthcare provider who is familiar with trigeminal neuralgia and other trigeminal neuropathic facial pain?

- The TNAA Medical Advisory Board includes experts in the field. You can contact them for an appointment or to recommend someone closer to you.
- Join the TNAA group on Facebook and ask members which doctors they see. Remember that each person chooses a doctor for different reasons and each patient has different outcomes of treatments.
- Contact one or more TNAA Support Group Leaders, to discuss their facial pain journey and which doctor(s) they consulted or attend an TNAA Support Group meeting and talk with other attendees about their experiences.
- Remember, you may need to travel to find the expert you need to see.

Non-neuropathic facial pain

Most facial pain is not neuropathic so a systematic approach to its diagnosis is essential. Non-neuropathic conditions that should be considered in the differential diagnosis include myofascial pain, temporomandibular joint disorder (TMD), dental disease (cavities or gum disease), cracked teeth (with exposed nerve roots), infections including sinusitis, and migraine headache.

Answering the question, “*What is this pain?*” can be frustrating for patients and doctors alike. Your expectations need to be realistic. A proper diagnosis could take a while. It is time well spent. You cannot treat the condition until you know what it is.,

Please refer to this Knowledge Sheet – Diagnosis Help Sheet as a training resource

Credit to the Facial Pain Organisation

[Seeking a Diagnosis - Facial Pain Association \(facepain.org\)](https://facepain.org)