

Trigeminal Neuralgia Association UK

Facing pain together

TRIGEMINAL NEURALGIA

AN OVERVIEW

The TNA UK was established to provide support and information to people affected by trigeminal neuralgia and we regret that we are unable to provide medical advice. The information contained in this booklet is for educational purposes only, to enable you to make informed decisions about your care in consultation with your physician. It should not be regarded as advice on diagnosis or treatment.

All information leaflets issued by the Trigeminal Neuralgia Association UK have been endorsed by the Association's Medical Adviser

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WHAT IS TRIGEMINAL NEURALGIA (TN)?

TN is an extremely severe facial pain that tends to come and go unpredictably in sudden shock-like attacks.

The pain is often described as stabbing, shooting, excruciating, burning, extremely strong.

The pain usually lasts for a few seconds, but there can be many bursts of pain in quick succession.

It is a chronic disorder of the trigeminal nerve (or fifth cranial nerve) and affects about 8 people in 100,000.

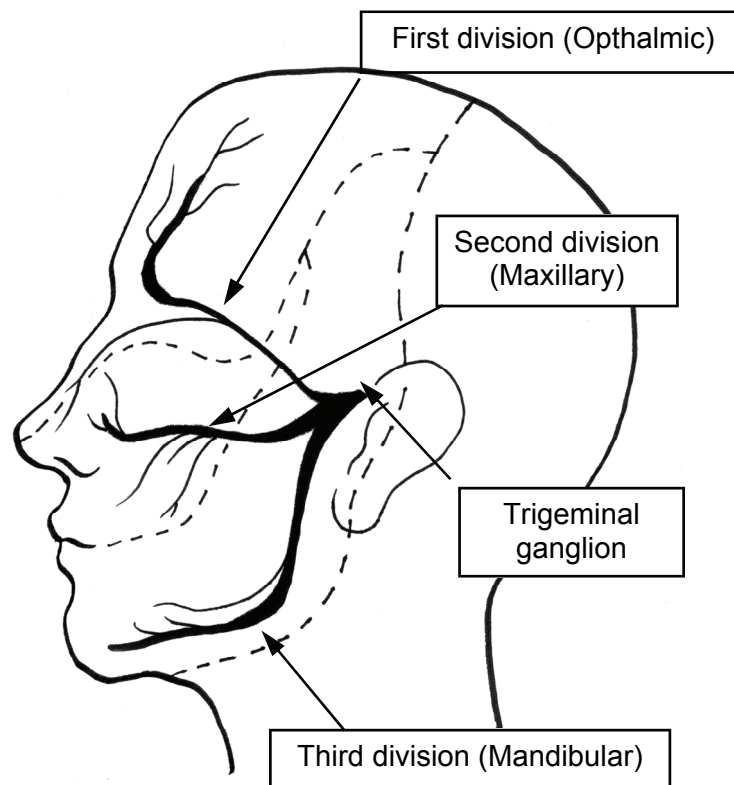
The Trigeminal Nerve has three branches (or divisions):

- The upper branch (Ophthalmic) which runs above the eye, forehead and front of the head.
- The middle branch (Maxillary) which runs through the cheek, upper jaw, teeth and gums, side of the nose.
- The lower branch (Mandibular) which runs through the lower jaw, teeth and gums.

TN can involve one or more branches. Most frequently, the middle and lower branches are affected. It usually affects people over 50 years old, but many cases have been reported in young adults, and very rarely among children.

It affects women more than men, and it is more often on the right side of the face.

It is not thought to be hereditary.



WHAT ARE THE CAUSES OF TN?

This is still an area for debate among the medical professionals. Most of them believe that the deterioration of the myelin (protective coating of the nerve) allows the transmission of abnormal messages of pain. The damage of the myelin sheath may be caused by pressure from blood vessels or arteries, tumours, Multiple Sclerosis, injury to the nerve, consequences of shingles, or just the ageing process.

DIAGNOSIS

If, after several visits to a dentist, a GP or an Ear-Nose-Throat specialist, TN is suspected, the patient is sent to a neurologist. He will perform some neurological tests to rule out or discover other diseases. He will also ask you for a precise description of the pain. Most doctors will recommend a MRI scan in order to see if there is any obvious cause.

Classic TN

- Spasms of sharp, stabbing pain, often described as like a jolt of lightning.
- The pain is confined in the area served by the branches of the TN nerve: lower jaw, upper jaw, cheek, eye, and forehead. The pain may include one, two or all three branches of the TN nerve.
- Pain is almost always on one side of the face, most commonly the right-hand side.
- The pain is usually provoked by a light touch on the face, movements of the face (and therefore mouth), touching the side of the nose, a light breeze. Trigger points are usually around the nose and lip.
- The pain might disappear by itself for weeks, even months, and return.

Atypical TN

- Aching, burning pain, mainly in the cheek, upper jaw and sometimes lower jaw. It is less likely to happen in the eye and forehead area.
- A trigger point is more difficult to define than in typical TN.
- Sometimes, after a long period, classical TN can also be accompanied with atypical TN. This leads to a combination of the sharp, electric shock-like pain plus the dull aching pain.

MEDICAL TREATMENT

There are various medical and surgical treatments for TN. The usual process is to start with medication, most commonly anticonvulsants, originally developed to treat epilepsy. Patients need to understand that these medications do not work like pain-killers: you need to maintain a therapeutic level of medication in your blood for effective relief of the pain. Regular blood tests are needed, in order to check the medication level in your blood. Taking the medication irregularly is not effective. To avoid severe side effects, the medication is increased or decreased slowly, according to your doctor's advice. After the patient is pain free for about three to six weeks, the medication is then slowly tapered. Abrupt withdrawal can lead to serious side-effects.

Always maintain good communication with your doctor when you are under medical treatment; it will allow him to find the right medication and the right dose you need to stop the severe attacks of pain.

The most commonly used anticonvulsants are: Tegretol (carbamazepine), Dilantin (phenytoin) and Neurontin (gabapentin). Baclofen (Lioresal) is sometimes used, although its primary use is for controlling muscle spasms. It is not as effective as carbamazepine but does have fewer side effects. Treatment can also include antidepressants such as Amitriptyline (Elavil).

SURGICAL TREATMENT

When medications are not working, or when severe side-effects are unacceptable, surgery is considered. You will need to be referred to **a neurosurgeon with experience in TN.**

Surgical procedures vary from nerve blocks through the cheek, open skull surgery or radiation. It is a difficult decision to make, and it is your referring doctor and neurosurgeon's duty to inform you on all procedures available.

Simple surgical procedures are used to damage the TN nerve, in order to block the electrical activity transmitting the pain. They involve passing a needle through the cheek under local anaesthesia. Then, the nerve can be bathed in glycerol (**Glycerol injection**), frozen (**cryotherapy**), heated (**thermococulation** or **radiofrequency rhizotomy**), or compressed with a small balloon (**balloon compression**). Those procedures leave a feeling of numbness in the face. The average period of relief varies from a few months to a few years. They can be repeated easily.

The other option is **Microvascular Decompression (MVD)**: An opening is made behind the ear, and the surgeon moves away all blood vessels or arteries compressing the nerve. It requires a general anaesthetic, and a minimum stay of one week in hospital. Numbness in the face is extremely rare. After an MVD, 95% of patients have immediate relief, and about 70% are still pain free 10 years later.

Gamma Knife is a fairly new procedure involving radiation beams targeted with high precision to the root of the nerve. Although the first results are promising, there is no long-term study on the success rate, and there are only three hospitals carrying out this procedure in the UK. But it has many advantages for the patient, as it is mostly pain free and non-invasive.

The usual process when you have TN is to try medication. Then, if pain persists or returns, you can consider having surgery. MVD is generally recommended to younger and healthy patients, because this is their best chance for long-term relief. Peripheral procedures are recommended for elderly or frail patients, or for those who do not want to take the risks associated with a major surgery but would accept a feeling of numbness in the face.

Having surgery is an important decision to make, and it should be discussed with an experienced neurosurgeon, who can explain all possible side effects and consequences of the operation. There is no procedure that is 100% sure to be effective. It is therefore important to receive clear and complete information before making a decision.

OTHER CAUSES OF FACIAL PAIN

Besides the array of dental problems that are sometimes confused with TN, there are at least two dozen other conditions that can cause facial pain.

Trigeminal neuritis

An inflammation of the trigeminal nerve that is often described as dull and burning, and sometimes as a crawling feeling. Either way, the feeling is usually constant, not fleeting. Diabetics are prone to get trigeminal neuritis. It is usually treatable with anti-inflammatory drugs.

Temporal arteritis

A chronic achy, throbbing feeling around an inflamed artery in the temple area. The area is very tender to the touch, and the pain is usually one-sided. It may lead to blindness if left untreated. Steroids such as prednisolone are typically used to treat temporal arteritis. Treatments are sometimes necessary for years.

Cluster headache

Burning, boring, piercing or tearing pain on one side of the head, often triggered by drinking alcohol. It is believed to be caused by dilation of arteries inside the skull. Most often affects men aged 18 to 40. Unlike TN, cluster headache attacks may occur during sleep. Pain, in fact, is often worse when lying down. Light touch does not tend to trigger pain.

Cluster headache typically occurs in a series of throbbing attacks that last 15 minutes to three hours at a time. Attacks may occur several times a day or every few days, then there is a remission. Attacks also tend to “cluster” in certain time periods, especially in spring and fall. Symptoms may also include tearing of eyes, stuffy or runny nose, flushing on the painful side of the face and, occasionally, sweating of the forehead. A variety of medications, sprays and inhalers are used to prevent and treat cluster headaches, including sumatriptan (Imitrex), ergotamine (Cafergot, Ergomar), steroids, nasal lidocaine, calcium channel blockers, and inhaled oxygen. Several surgeries designed to selectively damage the nerve or parts of the brain are available if all else fails.

Facial migraine

Pulsating, ice-pick-like pain that also occurs in throbbing attacks for hours or even days at a time. It typically affects nostrils, cheeks, gums and teeth, and the pain may be accompanied by an upset stomach. During facial migraine attacks, patients are also often highly sensitive to noise and light. Medications such as indomethacin (Indocin) and sumatriptan (Imitrex) are used to prevent and treat it.

Myofascial pain

Dull, aching constant pain in the jaw that is worst when chewing. It is an affliction of the jaw muscle rather than the nerves, that is often associated with frequent grinding or clenching of the teeth and jaws.

A key sign of myofascial pain is that the patient has tender jaw muscles and cannot open his or her mouth wide. Hard “knots” may develop on the jaw muscle. Other symptoms often include tearing of eyes, stuffy nose and trigger points that activate pain when pressed, rather than lightly touched as in TN’s trigger points.

Anti-depressant drugs may help. Local anaesthetic injections usually give temporary relief.

Atypical odontalgia

Dull, aching, throbbing or burning pain that is constant or nearly constant. Stimulating a tooth or teeth worsens pain so it is often confused with a toothache. Teeth appear normal however. The cause is unknown but sometimes treatable with anti-depressants. Most commonly affects women in their mid-40s and is often associated with depression.

Glossopharyngeal neuralgia

Very similar in symptoms to TN, only this pain affects a different cranial nerve – the one that serves the base of the tongue, throat, ear and base of the jaw. Most cases are thought to be caused by a blood vessel compressing the glossopharyngeal nerve, but in rare cases a tumour, multiple sclerosis or a calcified ligament could be compressing or damaging the nerve.

Attacks tend to occur in clusters followed by remissions. Talking, yawning and swallowing trigger the stabs. Anticonvulsant medications often help. Microvascular decompression of the glossopharyngeal nerve is also an option, as are procedures that sever the nerve.

Post-traumatic neuralgia

Stems from injury to a branch of the trigeminal nerve, such as through a fall, car accident or being hit by an object. The nerve can also be damaged during oral surgery, tooth removal, root canal or dental implant.

It often causes numbness instead of pain but can be a burning pain. Tough to treat but sometimes the nerve regenerates and heals itself. Antidepressants, anti-inflammatory and some anticonvulsants such as gabapentin (Neurontin) may help. Transcutaneous electrical nerve stimulation (TENS) treatments, topical anaesthetics and analgesics such as lidocaine and hot-pepper cream are also helpful in some cases.

Sinusitis

Inflammatory disease of the sinus that can refer pain to the upper teeth. Dull, constant tooth pain may accompany fever, nasal discharge and tiredness. Teeth and sinus area are usually tender to the touch. X-rays can be used to detect the inflammation. Antibiotics, decongestants, antihistamines, and in severe cases, surgery are used to treat it.

Cluster tic syndrome

A blend of three types of pain – sharp stabs like TN, throbbing pain and related symptoms of cluster headaches, and a one-sided headache that follows the sharp stabs. Some say it is actually a dual case of TN and cluster headache, while others say it is a distinct condition probably caused by damage somewhere along the trigeminal nerve's path. TN medications – especially the ones that help atypical cases – often help, but this one occasionally resolves itself.

Temporomandibular joint disorder (TMJ or TMD)

Muscle pain in the jaw believed to be caused by injury to the joint, arthritis, grinding of the teeth, muscle tension, stress or possibly teeth that do not meet properly. Pain occurs mainly when jaw moves or is touched. Chewing is a particular aggravating factor. TMD also affects twice as many women as men. Treatments include hot and cold packs, massage, muscle relaxation techniques, anti-inflammatory and muscle-relaxing medications, dental appliances and, if all else fails, surgery.

Chronic paroxysmal hemicrania

Similar to cluster headaches, only attacks are shorter lasting and more frequent. It occurs mostly in females. Attacks last five to twenty minutes and occur during periods of between 15 to 24 hours. Often treated with the drug indomethacin (Indocin).

Superior laryngeal neuralgia

Rare condition that may be an offshoot of glossopharyngeal neuralgia. Pain is in side of throat, beneath jaw and under the ear. Swallowing, shouting or turning the head may bring on pain. Sometimes a trigger point is present on the side of the throat. Condition sometimes goes away on its own after a few days.

Geniculate neuralgia

Bouts of severe pain deep within the ear. Pain is often prolonged rather than brief and stabbing, but it often responds to the same treatments as TN, especially carbamazepine (Tegretol).

Occipital neuralgia

Pain at the back of the skull and up towards the ear and top of the head on one side only. It can be caused by trauma, by arthritis-related compression of the occipital nerve, or by a tumour on, or pressing on, the nerve. The pain is often more prolonged and throbbing than brief and stabbing. Achiness may persist between sharper attacks, but pain is usually not as severe as in other neuralgias. Condition can often be relieved with a local anaesthetic. If a tumour is found to be causing the problem, removal is an option. Otherwise, sharp pain attacks often respond to anti-convulsants such as carbamazepine (Tegretol) and more constant pain may respond to tricyclic antidepressants such as amitriptyline (Elavil), nortriptyline (Pamelor) or desipramine (Norpramin).