



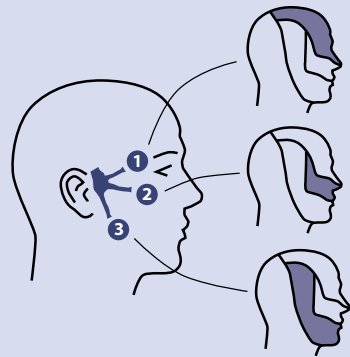
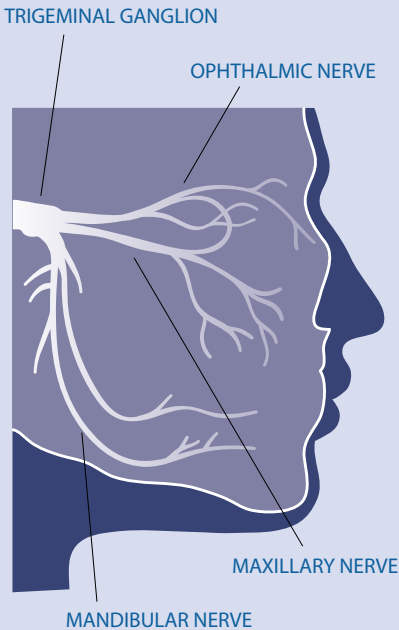
An Introduction to

TRIGEMINAL NEURALGIA

www.trigeminalneuralgiawa.com.au



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Each trigeminal nerve has three branches that conduct sensation from the upper, middle and lower portions of the face to the brain

UNDERSTANDING TRIGEMINAL NEURALGIA

Trigeminal Neuralgia (TN) is a chronic disorder that usually affects people in middle or later life and only rarely in children or young adults. It is an excruciating facial pain that tends to come and go in sudden shock-like attacks and is due to a chronic disorder of the trigeminal nerve (5th cranial nerve) which is the largest of the body's 12 pairs of cranial nerves.

The trigeminal nerve has three branches which conduct sensation from the upper, middle and lower portions of the face and also the oral cavity, to the brain.

The painful attacks of TN can involve one or more branches. Most commonly the middle branch or lower branch either individually or in combination with each other are involved. Only about 4% of patients experience pain in the upper branch. In rare instances, all three branches may be involved. The right side of the face is more frequently affected than the left and in a small percentage of patients, pain occurs on both sides of the face, but rarely at the same time.

Since the largest per cent of the patients have involvement of the middle and lower branches, many of the initial symptoms are felt in the teeth and gums. This period, sometimes referred to as pre-trigeminal neuralgia presents a considerable diagnostic challenge, especially for dentists since they are, quite often, the first health professional to see the patient.

While true dental abnormalities do produce pain, the pain of TN is not caused by dental problems. What may appear as a toothache may actually be an early symptom of TN.

It is not unusual for a TN patient to see half a dozen or more dentists, oral surgeons, ear nose and throat and TMJ specialists etc. Many mode of treatment – root canals, extractions, oral surgeries etc – are pursued, to no avail, while the pain steadily worsens and more classic symptoms of TN develop.

TN is generally considered to be the most painful of all human afflictions but fortunately it is not fatal; rather it is a treatable disorder that can be effectively managed, and often times, long term control can be achieved.

POST HERPETIC NEURALGIA

Sometimes, facial pain can occur after shingles particularly if treatment with anti-viral medication is not commenced as soon as shingles is detected.

Post herpetic pain tends to be more constant than classic TN and also will often strike the eye/forehead region more than the cheek and lower jaw regions. This type of pain almost always goes away in time. It may be months for some or one or more years for others but rarely lasting more than five years

SYMPTOMS AND CAUSE OF TN

SYMPTOMS

Classic TN has distinct symptoms which clearly separate it from other forms of facial pain

- Pain in short, acute bursts rather than dull, constant ache. Often described as electric shock-like in nature
- Pain is usually triggered by light touch or sensitivity to vibrations such as brushing teeth, shaving, a light breeze, a soft kiss, talking etc.
- The pain has a tendency to come and go with periods of intense, sometimes totally debilitating pain, followed by complete pain-free periods of remission lasting from weeks to months or possibly longer.
- Most patients experience pain during the day while they are up and about. Generally, they are pain-free while asleep unless triggered by the touch of bed linen or changes in position.

The patient history and description of symptoms are the doctor's major aids in confirming the diagnosis of TN. Most doctors will recommend a head/brain MRI or CAT scan along with other laboratory tests. These are conducted mainly to rule out other possible causes of the pain such as tumours, multiple sclerosis etc. There is no specific test available to confirm the diagnosis of TN.



CAUSE OF TN

There are several theories on the cause or causes of TN, but not one that is universally accepted by all medical professionals. The majority of specialists believe that the protective covering (myelin sheath) of the trigeminal nerve deteriorates allowing abnormal messages (pain) to be sent along the nerve. The main cause of this deterioration is usually due to a blood vessel pressing on the trigeminal nerve where it enters the brain stem. In a few cases, TN occurs as a result of a tumour or multiple sclerosis but these are relatively uncommon. The deterioration causes the nerve to send abnormal messages to the brain – like static in a telephone line. These abnormal signals disrupt the normal signal of the nerve and cause pain.

DIAGNOSIS OF TN

As TN is not a common complaint and there are many other types of facial pain, we recommend that you seek a referral to a neurologist for a diagnosis of the pain and the prescribing of the medication most suited to the pain.

TN is not always easy to diagnose because it can mimic many other possible problems

especially in the early stages. Unlike many afflictions, there is no blood test, x-ray or other test that tells you that you have TN. It is diagnosed by the patient's description of the symptoms and by ruling out other things. Therefore it is important to provide the doctor with a clear description of the pain.

ANSWERING THESE QUESTIONS WILL ASSIST THE DOCTOR IN DIAGNOSING YOUR PAIN

- Is pain predominately in your face – ie forehead, eye cheek, nose, upper/lower jaw, lips etc
- Is pain only on one side of your face
- Is pain entirely or mostly brief
- Is it electrical, shocking, stabbing, shooting
- Do you have constant background facial pain eg aching, burning, throbbing, stinging and is it for more than half of your waking hours
- Can your pain start by something touching your face eg by eating, washing your face, shaving, brushing your teeth etc
- Since the pain started, have you ever experienced periods of weeks, months, or years when you were pain free (This does not include periods after pain relieving surgery or while on medications for the pain)
- What medicines are you taking for the pain? List and include over the counter ones, the dosage and time of day taken
- Did you experience any major reduction in facial pain (partial or complete) from taking any of these drugs. Were there any side effects?
- Did your pain start after shingles
- Do you have multiple sclerosis
- Did your pain start after a facial injury
- Did your pain start only after facial surgery (ie oral surgery, ear/nose/throat surgery or plastic surgery)
- When you place your index finger right in front of your ears on both sides at once and feel your jaw open and close, does the area under your fingers on either side hurt

MEDICATION

Many patients find that TN can be effectively managed with medication. Even though the pain of TN may come and go, it is necessary for a TN patient to take medication regularly to prevent the sudden onset of an attack. Taking medication sporadically is ineffective, and abrupt withdrawal of medications can cause side effects.

Once a patient has been pain free for four to six weeks, the medication may be gradually tapered off but only on your doctor's advice.

Analgesics (such as aspirin and Nurofen) and narcotics are ineffective against TN because attacks are usually sudden and long term use of narcotics is not advisable.

Anticonvulsant medications which slow down the nerve's conduction of pain signals are usually the first treatment option for classical TN.

Carbamazepine (Tegretol) has been the primary drug used to treat TN. Many neurologists believe that the relief of facial pain with Tegretol confirms the diagnosis of TN. The drug is introduced slowly and increased by the doctor to a level where the patient is pain free or side effects occur. It has been shown in controlled clinical trials to be effective in approximately 60% of patients with TN.

Phenytoin (Dilantin) is another drug that is used to treat TN, especially if the patient has had adverse side effects to Tegretol. Since Dilantin may also be administered intravenously, it is sometimes used to stop an acute attack, such as in the emergency room. Dilantin is considered to be less effective in addressing TN, but it may be better tolerated by the elderly patient.

These drugs, which are also used as anticonvulsants, generally are thought to work by blocking the firing mechanism of the nerve. The more common side effects are dizziness, drowsiness, forgetfulness, unsteadiness and nausea. Serious side effects may occur although they are rare. They include anaemia, liver toxicity and kidney dysfunction. Patients on Tegretol and Dilantin should have periodic blood counts to monitor any blood abnormalities.

Gabapentin (Neurontin) is a more recent anticonvulsant. Since it is eliminated by the body rather than metabolized it is felt to be more easily tolerated and to cause less liver toxicity. Neurontin has also been found to be beneficial in the treatment of some atypical facial pain syndromes and other painful nerve problems.





Pregabalin (Lyrica) is a successor to Gabapentin (Neurontin) and is chemically similar to that drug. It is said to be as effective as Neurontin, but at lower doses, which should translate to fewer side effects.

Other medications used in the treatment of TN may include Baclofen (Lioresal), clonazepam (Rivotril) and sodium valporate (Epilim).

During all phases of medical treatment, patients need to communicate their pain level and / or drug side effects to their neurologist or other 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, including seizures, anticonvulsant dosages must be increased and decreased slowly as directed by your doctor. Do not stop these medications abruptly. The drugs tend to work on an all or nothing principle. They do not give partial relief as the dosage is increased; they work when the correct dosage is reached, so dosage must be individualized with each patient.

Anticonvulsants can be given in combinations. Neurontin and Baclofen are often given as a second drug along with one of the other anticonvulsants.

Alcohol and other sedatives should be avoided with most of these drugs.

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

Long term use of anticonvulsant drugs have been found to deplete bone mass, leading to osteoporosis, so bone density testing and calcium supplements are recommended.

About 80% of TN patients will respond to medications and find their TN symptoms can be effectively managed with drugs; however, 20% will not. Consult your neurologist for complete information regarding medication dosages and specific questions about them.



SURGICAL OPTIONS

A sizable number of TN patients achieve long term relief from medication. Those for whom medication does not provide relief or those who suffer unacceptable side effects from medication, may want to consider surgery.

There are several surgical interventions used to treat TN, none of which is 100% effective in all cases. Collectively, these procedures have an initial response rate of about 80%, with approximately 25% of patients experiencing some level of recurrence within one to five years. Many of these patients respond very well when surgery is repeated or other medical management is pursued.

The surgical techniques used to treat TN range from procedures performed at day surgery to damage the nerve to that of invasive surgery that requires a hospital stay of several days' duration. Determining which procedure is the best choice for a particular person should be based on several factors such as the patient's preference, physical well being, previous surgeries, presence of multiple sclerosis, and area of trigeminal nerve involvement particularly where the upper/ ophthalmic branch is involved. Undoubtedly, recommendations by the neurologist or neurosurgeon will play a strong part in the patient's decision making process. The Support Group is not an advocate for any individual mode of treatment, but serves to provide information on the various treatments available so that patients can explore all their options



RADIOFREQUENCY RHIZOTOMY

This is one of the most effective and safest procedures for relieving TN pain. During the procedure – which is usually performed on an outpatient basis while the patient is sedated – an electrode designed to destroy the part of the nerve that causes pain is placed on the nerve using a needle inserted through the cheek. A moderate amount of numbness around the area where the pain was located is an expected side effect of this procedure.

Statistics overseas have indicated that after 5 years, 50% of patients were pain free.

GLYCEROL RHIZOTOMY

This procedure is similar to radio frequency rhizotomy. Instead of inserting an electrode into the nerve, the surgeon injects an alcohol substance, called glycerol, which bathes the nerve and damages the pain fibres. As with the radio frequency rhizotomy, minor numbness can be expected following this procedure.

Statistics have indicated that this procedure is less effective than the radio frequency rhizotomy with less than 50% pain free after 4 years.

BALLOON COMPRESSION

This again is a similar procedure but in this case a tiny balloon is inserted through a catheter into the trigeminal ganglion (the central part of the nerve that transmits nerve impulses) and then inflated. The inflated balloon compresses the nerve and damages the pain fibres. Again minor numbness may result.

MICROVASCULAR DECOMPRESSION

This is the most invasive of all surgical options to treat TN, but it also offers the lowest probability that the pain will return within 5 years. This surgery aims to remove the cause of the problem rather than damaging the nerve.

With the patient anaesthetized, a small opening is made behind the ear. While viewing the trigeminal nerve through a microscope, the surgeon places a soft cushion (typically shredded Teflon) between the nerve and the blood vessels that are compressing it.

The procedure usually takes two to four hours and patients can expect a hospital stay of at least two to five days.

Statistics have shown that in excess of 80% were pain free, either with no medication or some medication, after 5 years.

ALTERNATIVE / COMPLEMENTARY TREATMENTS

There are a number of alternative treatments that may assist in alleviating the pain and reducing the need for drugs or surgery. Often sufferers will seek alternative treatments because of lack of effectiveness or side effects of the drugs or due to failed surgery. Some may be suffering from atypical TN pain for which drugs or surgery may provide only limited pain relief.

As an example, several members of the support group have achieved pain relief from kinesiatrix remedial massage treatment



TRIGEMINAL NEURALGIA SUPPORT GROUP WA INC

WHO WE ARE

The Support Group commenced in 1990 with the aim of providing information, mutual support and encouragement to persons suffering from Trigeminal Neuralgia (TN) and related facial pain conditions.

At that time, TN was little known in the community due mainly to the fact that it affects only about one in every 20,000 people. Because of the excruciating pain, sufferers felt isolated and lacking knowledge of the medication, surgical and other options available to alleviate the pain.

The group has grown to more than 100 members and conducts meetings on a six weekly basis at Perth and Midland with contact points in regional areas.

The purpose of these meetings is to hear medical professionals speak on the latest developments in treating TN and to share the experiences of members.

The group is affiliated with the Trigeminal Neuralgia Association (TNA) in the United States which is conducting substantial research on all aspects of treating TN.

A newsletter is sent to members prior to each meeting and contains information from TNA and other sources to assist members, particularly those unable to attend the meetings. The group has developed an extensive library of books, and also video tapes and DVD's of addresses given by medical professionals to the group or at TNA conferences in the US which are conducted every two years.

Membership is \$20pa to cover printing and postage of the newsletter and persons seeking an application form should contact the Treasurer or Secretary.

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