

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?

The official description of Trigeminal Neuralgia (TN) is: *“sudden, severe, brief, stabbing pain occurring in attacks lasting at the most a few seconds usually only on one side of the face and provoked by light touch”*. It is considered to be “the worst pain known to man” and attacks are often described by patients as being like ‘an electric shock’, which may be severe enough to rivet them to the spot or bring them to their knees. The pain can also be described as stabbing, shooting, burning, excruciating, and unlike any other pain previously experienced. The pain attacks may last for a few seconds or occur in “volleys” — multiple bursts of pain in quick succession — lasting several minutes. The pain, often triggered by just a light touch to an area of skin, can strike at any time and without warning. Frequency of attacks can vary from a few times a month to several times each day depending on the severity of the condition. Unfortunately, for most sufferers, the condition is progressive and will worsen over time. Although to date there is no guaranteed cure for the condition, there are a number of treatments which can give relief.

WHERE IS THE PAIN FELT?

The pain is most commonly felt on one side of the face (unilateral) and usually in the cheek or lower jaw. There may also be pain inside the mouth and often it can feel as if it is coming from one or more teeth, hence many people seek the help of their dentist initially and some may undergo unnecessary dental treatment before getting a correct diagnosis. In other instances, pain can be felt on the entire side of the face or, occasionally, just around the eye and forehead. TN tends to affect the right side of the face more than the left side. Very rarely, it can occur on both sides (this is known as bilateral) but it is rare to have acute pain on both sides at the same time.

WHAT ARE THE CAUSES OF TRIGEMINAL NEURALGIA?

Although there is still much debate among neuroscientists regarding the causes of TN, it is now generally agreed that the trigeminal nerve is ‘misfiring’ and is sending out inappropriate pain signals. The trigeminal nerve can be thought of as being like an electric wire or cable that contains numerous fibres conveying different messages to the brain. There are pain, touch, temperature and vibration fibres, each insulated from one another by a protective sheath called myelin. The myelin sheath can be damaged by pressure from blood vessels (veins or arteries), multiple sclerosis (MS), injury to the nerve or simply as part of the ageing process. In a small number of cases, the cause may be due to a tumour or a benign growth pressing on the nerve.

When the nerve is injured it becomes ‘hyper-excited’. The result is that the nerve fibres inside the nerve itself fire off signals of pain at the least provocation. Pain fibres can “short circuit” with touch fibres, due to loss of insulating myelin, and this results in a “sparking” between the two, sending incorrect pain signals to the brain. The myelin tries to heal itself and this sometimes results in successive periods of remission when no pain occurs.

MORE ABOUT THE TRIGEMINAL NERVE

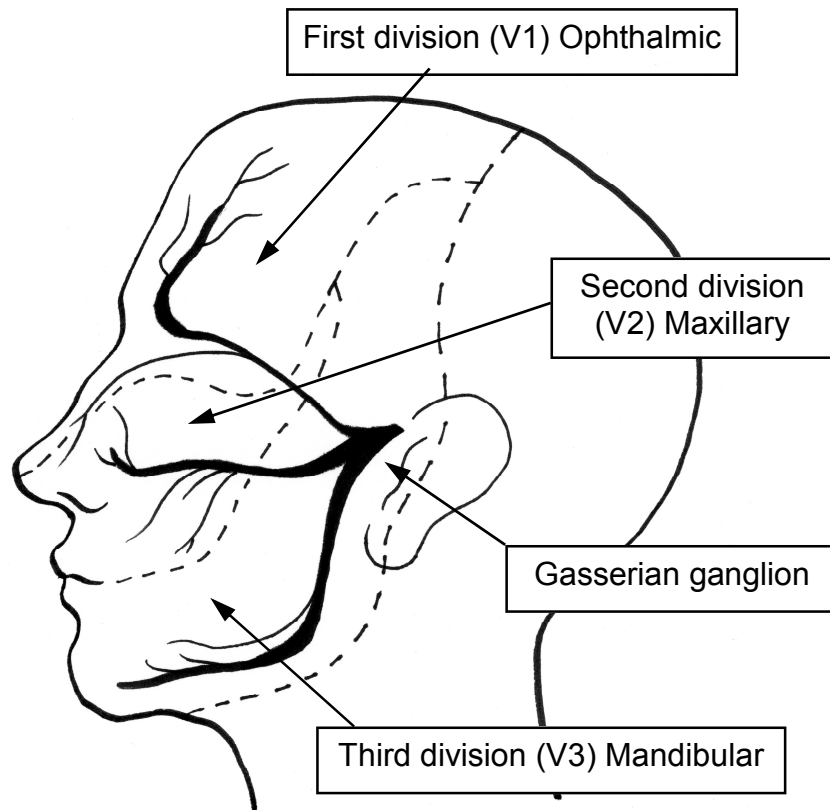
There are 12 pairs of nerves called the cranial nerves which provide the nerve supply to the right and left sides of the head and neck. The trigeminal nerve is the fifth and largest of these and is known medically as 'V' since V is the Roman numeral for five. Its job is to provide nerve sensation from the mouth, face and the front of the scalp, as well as controlling the muscles which are used in chewing (mastication). The trigeminal nerve allows us to experience touch, temperature and pain in the face. It does not affect the way the face looks; that is a different cranial nerve.

There are numerous small nerve fibres in the face which pick up sensations and transmit them to the brain. These fibres progressively gather together into three main branches on either side of the face. These are referred to as V1, V2, and V3:

- The *ophthalmic branch* (V1) which runs through the eye, forehead and nose
- The *maxillary branch* (V2) which runs through the upper teeth, gums, lips, cheek, lower eyelid and side of the nose
- The *mandibular branch* (V3) which runs through the lower teeth, gums and lip

These three branches then enter the brain through a hole inside the skull and join up to form what is known as the Gasserian ganglion. The whole nerve then continues to the back of the skull to enter the brain.

Diagram showing the trigeminal nerve and the three divisions



The dotted lines indicate the areas from which sensations are collected by the nerve.

HOW TO GET A DIAGNOSIS

The diagnosis can be made by your GP or dentist. It is crucial to give a thorough description of the pain. If the pain is too severe and affects your ability to speak, write things down and take someone with you who understands your condition. The following tips may help you to put together a synopsis of your pain:

- *When did the pain start and what were you doing at the time?*
- *What does the pain feel like; stabbing, shocking, burning, piercing?*
- *How often do you get the pain and how long does each attack last?*
- *What happens to you when the pain hits?*
- *Where is the pain starting from—in your teeth or actually around one tooth, your cheek, your nose, on the outside of the face or inside your mouth?*
- *Is there anything which sets the pain off or triggers it?*
- *How is the pain affecting you and the quality of your life?*
- *Does it ever cause visible effects, eg, watering or redness of the eye, swelling of the eyelid, runny nose and sweating?*

If TN is suspected you will need to see a neurologist, oral physician or pain specialist. An MRI scan is usually done to ascertain if there is an obvious cause for the pain and also to rule out other conditions. As there is no diagnostic test for TN, the procedure of diagnosis may take some time and require persistence.

A TN diagnosis falls into two categories: Classic TN, also referred to as Idiopathic TN, or Symptomatic (secondary) TN.

Classic Trigeminal Neuralgia

This is typically caused by a blood vessel or vessels compressing the trigeminal nerve as it enters the brainstem. The loss of the myelin sheath surrounding the nerve will have been caused by the constant rubbing and pulsating of the blood vessel(s), causing erratic messages to be transmitted along the wrong nerve fibres, ie, “cross talk” between light touch and pain fibres. It is established that the majority of TN cases are caused this way. It is likely that the offending vessels will be identified on an MRI scan, although this is not always the case. This type of TN results in clearly identifiable triggers which can provoke pain attacks. These triggers can include:

- Brushing teeth
- Yawning
- Swallowing
- Face washing
- Shaving or putting on make-up
- Vibration or sudden movement, even walking
- Exposure to cold, a breeze on the face or air conditioning
- A light touch to the affected area
- Eating or biting into something
- Talking or smiling
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This is not an exhaustive list and attacks also happen spontaneously with no obvious trigger.

Symptomatic Trigeminal Neuralgia

This includes cases where TN is secondary to an underlying cause such as:

- Multiple Sclerosis (MS) which may also result in the demyelination of one or more branches of the trigeminal nerve and lead to TN.
- Other rare diseases which cause damage to the myelin sheath such as benign cysts, a tumour compressing the trigeminal nerve, abnormalities at the base of the skull or arteriovenous malformations, ie, abnormal blood vessels.

Only a very few trigeminal neuralgia cases are caused by one of these underlying medical conditions.

Trigeminal neuralgia is different to *trigeminal neuropathy*. The latter is a pain syndrome which has resulted from injury to the trigeminal nerve, causing pain with numbness. Examples of causes are surgery involving the teeth or sinuses, infections or trauma to the face and head.

WHAT ABOUT TREATMENT?

Controlling the symptoms of TN

Even before diagnosis, it is possible that you will have been placed on medication due to the excruciating nature of the pain. The usual range of painkilling medications, even morphine, have no effect so it is necessary for you to be prescribed *anticonvulsant drugs* (used to treat epilepsy) - the first-line one being carbamazepine - and sometimes *antidepressants*. These drugs were never specifically designed for TN but they “dull down” the nervous system dramatically. It is important to start on a low dose of medication and **very gradually**, over a number of days or weeks, increase the dose until hopefully the pain is under control or relieved altogether.

Dosages should be monitored by your medical practitioner and certain medications require regular blood tests. Sometimes, a mixture of medication may be prescribed, depending on your type of pain. You may have to try a few medications before finding the one best suited to you. Anticonvulsants do have side effects and it is common for TN patients to experience drowsiness, dizziness, unsteadiness, confusion, blurred vision, memory problems, difficulty in concentrating and nausea.

It is also possible to have an extreme allergic reaction to some anticonvulsants. In this case, which can involve a serious rash, you should seek urgent medical attention. However, it can sometimes be dangerous to cease medication suddenly, so always visit your medical practitioner if you have any concerns, especially if you are feeling very depressed.

Surgical treatment

If your pain persists after a few months on the medication, or if the side effects are so serious that your quality of life has become significantly impaired, a surgical procedure may be an option for you. TN may have a significant and adverse effect on the quality of your life. You may be living in fear of another attack and you may feel isolated and alone.

You may also begin to feel very despondent through your inability to function as an individual. If so, it will be necessary for you to make an informed decision about your future treatment and this may include surgery. However, please bear in mind that certain surgical procedures are not suitable for anything other than classic trigeminal neuralgia and if you do not have the correct diagnosis, surgery may make your situation far worse.

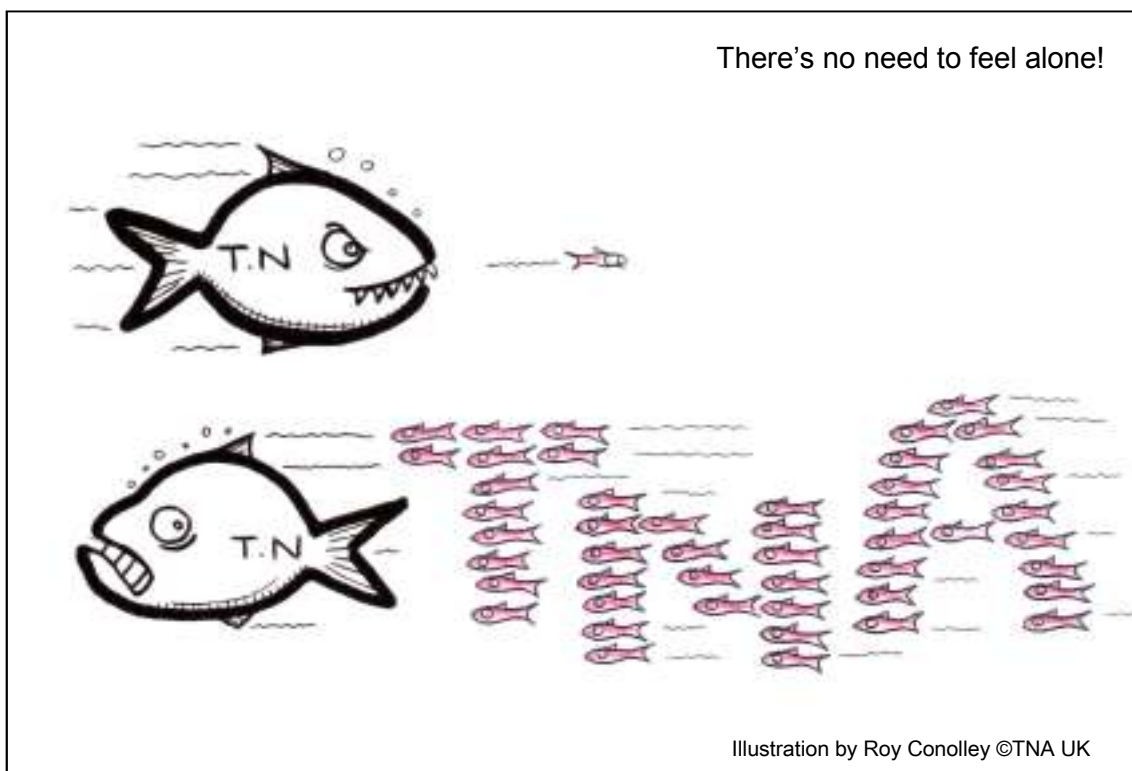
Surgery can broadly be split into two categories: non-invasive and invasive. Non-invasive surgeries include injections through the cheek (commonly known as percutaneous procedures) and Gamma Knife, which does not involve an incision but is a dose of radiation. Invasive surgery is Microvascular Decompression (MVD) which involves opening the skull and lifting the offending blood vessel(s) away from the nerve.

Whichever option you decide upon, it is important to recognise that all procedures have risks. Before making any decision, it will be necessary to research your options thoroughly and in conjunction with your medical practitioner. If you wish to explore the surgery options, it is advisable to see a neurosurgeon. This can be arranged through your GP.

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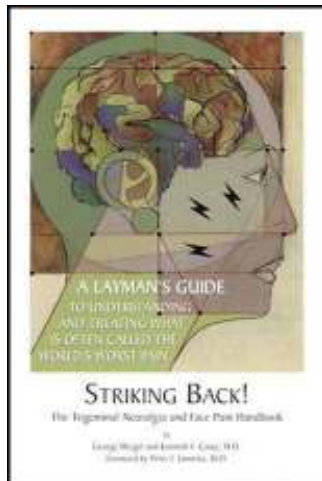
TNA UK has separate leaflets about each of the surgical procedures as well as the various medications used to control TN. You may also find it useful to talk to others who have had similar experiences, and can offer tips and advice.

If you wish to find out more about TN please contact TNA UK at the address on the inside cover, or visit www.tna.org.uk.

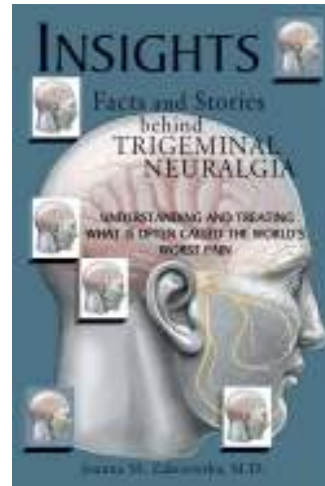


Two excellent books are available from TNA UK:

Striking Back—the layman’s guide to understanding and treating what is often called the world’s worst pain



Insights—Facts and stories behind trigeminal neuralgia



The authors are George Weigel, an American journalist and TN patient and Dr Kenneth Casey, a neurosurgeon who has worked closely over many years with Dr Peter Jannetta, the ‘Godfather’ of the MVD (microvascular decompression) procedure. This book gives full details about trigeminal neuralgia and other types of facial pain in a way that is understandable to medics and non-medics alike. For anyone suffering from TN, this is compulsive reading. Armed with the detailed information in this book, individuals are helped to make more knowledgeable choices about their care and treatment.

Written by Professor Joanna Zakrzewska, one of the world’s recognised authority on TN and Medical Advisor to TNA UK. The publication details patients’ experiences and scientific data, and provides an illustrated roadmap from diagnosis to the best available medical and surgical treatments, as well as practical tips on coping with recurrent pain. The focus is very much on the *person* with TN and the book includes guidelines for creating more effective patient care. It is a useful reference for sufferers, their families and carers, as well as for healthcare professionals seeking to help their patients.

These books cost £20.50 each, or £39.00 for the two together, including postage and packing, and can be ordered by sending a cheque to:

TNA UK, PO Box 234, Oxted, Surrey RH8 8BE

or by downloading an order form at www.tna.org.uk.

Other items are also available; please see our website for details.