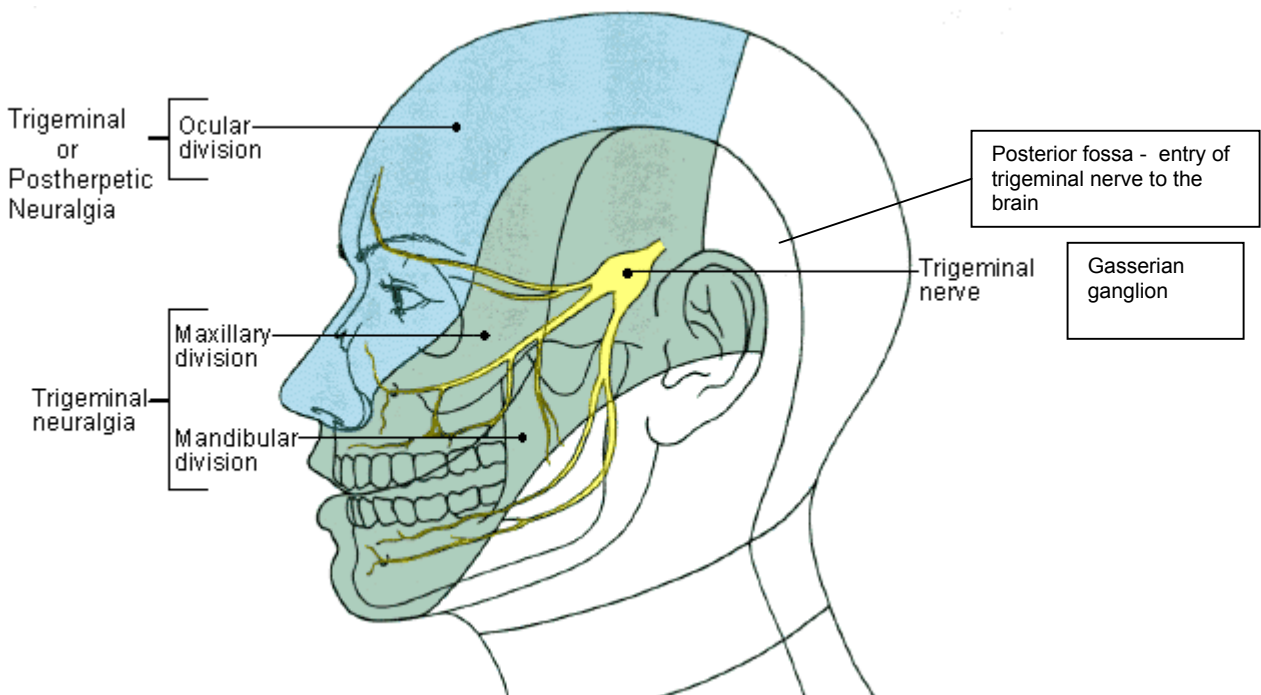


Trigeminal Neuralgia

What is trigeminal neuralgia?

Trigeminal Neuralgia is a condition that affects one of the large nerves in your head, called the trigeminal nerve. It is characterised by a sudden brief, severe, electric shock-like or stabbing pain typically felt on one side of your face, provoked by light touch, which may remit for varying periods. It is more common in women than in men and usually affects people aged 50 and older. It is a rare disease affecting around 0.7% of the population.

There are 12 major nerves on each side of your head. These are called cranial nerves. Each one has a different function. The trigeminal nerve is the fifth cranial nerve. It is responsible for sending impulses of touch, pain, pressure, and temperature to your brain, from your face, jaw, gums, forehead, and around your eyes. They also supply the muscles that help you to eat. Although you have two trigeminal nerves, almost always only one of them is affected, in trigeminal neuralgia. Only 3% of patients get bilateral pain and it is rare to get it at the same time.



There are three main branches to each of the trigeminal nerves. The area that each branch receives signals from is labelled on the diagram. In trigeminal neuralgia it is typically one or both of the lower two branches that are affected. The pain may be felt on the outside of the face or it may feel like toothache and be felt inside your mouth.

The pain is typically described as a sudden electric shock-like or jabbing,stabbing pain that lasts for seconds but which may be repeated as a salvo or volley. The pain attacks may come and go throughout the day and last for days, weeks or months at a time, and may then disappear for months or years. You may have a specific area called a trigger area that especially seems to start up the pain when stimulated.

Various actions may trigger the pain:

- lightly touching the skin on the side of your face;
- cold air on your face
- washing, shaving.
- eating;
- talking;
- tooth brushing;

The pain can be severe and disabling, sometimes preventing washing or shaving the affected side or applying makeup. Some sufferers may stop eating during these periods because they fear they might trigger a painful attack. You may also be unable to brush your teeth on that side. If the pain is left untreated or is unmanageable, weight loss and other complications could result.

What are the tests that detect trigeminal neuralgia and what is its cause?

A diagnosis of trigeminal neuralgia depends entirely on the history given by you. The cause of trigeminal neuralgia is, in most patients, either unknown or due to irritation of the trigeminal nerve by a blood vessel pulsating next to it. It is suggested that this pressure results in the insulation between nerves (similar to electric wires) to be partially destroyed and this allows nerves that normally only transmit light touch to send their impulses via nerves that transmit pain. Rarely, however, the pain can be due to a benign tumour pressing on the nerve, or to multiple sclerosis destroying the insulation. Your doctor will therefore want to conduct a thorough history and examination. He may request a brain scan such as an MRI or do other tests to exclude multiple sclerosis or a tumour or to see if there is a blood vessel pressing on the nerve.

What is the treatment for trigeminal neuralgia?

Drugs

The most useful group of drugs for this condition are anticonvulsants. It has been found that normal pain killers do not help this pain.

Carbamazepine is effective in around 70% of patients but either tolerance or increased severity of the pain makes the drug ineffective in the long term in some patients. Anticonvulsants such as *phenytoin*, *lamotrigine*, *oxcarbazepine*, *gabapentin* or *topiramate* have been used but not all have been tested in high quality trials to assess whether they really are beneficial. Other non anticonvulsant drugs used have included *baclofen* and topical *capsaicin* cream. *Clonazepam*, *pimozide*, *tizanidine* and *valproic acid* are not usually used because they cause severe side effects. Sometimes a combination of drugs can be used to achieve relief.

All patients when on medication are likely to have side effects, the average number of side effects is three. The main side effects are drowsiness, tiredness, feeling like a zombie, unable to concentrate, being uncoordinated. About seven percent of patients become allergic to carbamazepine. The likelihood of side effects is greater if you are on higher doses of the drugs. The side effects are reversible when you stop the drugs. The drugs are safe to use for many years provided you have occasional blood tests especially when using high doses. When using these drugs it is important to raise and lower the doses slowly over a number of days. If you are taking carbamazepine it is especially important to tell your doctor and dentist as this drug can interfere with other drugs they may wish to prescribe. It is a good idea to keep a pain diary so you know how the pain responds to treatment and when the drugs are no longer having an effect. In this diary you can record your pain severity on a scale of 1 to 10 and also note how frequently the pain occurs, what side effects you are getting and the dosage of the drugs you are taking.

Surgical treatment

If medication fails to help or you develop intolerable side effects from the drugs, surgical treatment may be recommended.. Most surgical procedures aim to interrupt or block the electrical activity of the nerve and hence stop the pain. There are several different effective surgical procedures, but all of them carry some risk of failure or complication. It is still not clear whether those patients having surgery earlier rather than later in the course of the disease do better long term. Some neurosurgeons suggest that the changes which occur to the nerve due to long-term compression may be harder to reverse if they have been present for longer.

What are the possible complications of surgery?

All surgical procedures have a certain element of risk and not all procedures have the same complications, some are specific to particular treatments, some are short term others are long term. All procedures may result in recurrence of pain. Complications include:

- cranial haemorrhage leading to a stroke
- eye infections due to loss of sensation
- hearing loss on one side
- difficulty with eating
- surgical-wound infection; generalised infection
- loss of sensation or alteration in sensation on one side of the face
- anaesthesia dolorosa ie, continuous pain in an area that is numb.

Surgical treatments that are available include:

Peripheral surgery

This surgery is done very close to where the trigger area is located : cryotherapy, alcohol block, laser, neurectomy. Most of them are done under a local anaesthetic and some will require the use of stitches inside the mouth. These give short term pain relief , around 10 months on average, and cause few complications. Many patients, however continue to need medication. They are now rarely used and are only suitable when other procedures are not possible.

Minor surgery

This is termed non invasive surgery as no cutting is done , instead an instrument is passed just inside the skull under Xray control to enter the Gasserian ganglion (see diagram above). This is done under a short anaesthetic and you can normally go home the next day.

In order to relieve the pain nerve tissue is damaged using one of the following procedures :

- *Radiofrequency thermocoagulation* – passing a current through the nerve which generates heat
- *Glycerol injection* – bathing the nerve in a toxic substance which over a few days destroys the nerves transmitting pain
- *Balloon micro compression* – the nerve is compressed by a small balloon which is blown up for a few seconds

All have relatively few side effects but the majority result in numbness of varying degree and extent. The most severe side effect is anaesthesia dolorosa. If the numbness affects the eye then special protective glasses must be worn to stop the eye getting scratched. There is least numbness after a glycerol injection. Pain relief is in the order of 3-4 years, shortest for glycerol injections. All the procedures are repeatable.

Major Surgery

This surgery is carried out on the back of the skull behind the ear it is done under a full general anaesthetic. Many patients can now have special investigations done (MRI or MRTA) prior to surgery which will tell the surgeon whether a compression is present.

- *Microvascular decompression* - the only procedure that does not attempt to destroy the nerve but lifts of a blood vessel that is pressing on the nerve inside the brain (see diagram above). It leaves a scar in the hairline behind the ear. It gives the longest pain relief around 8 years for 50% of patients. It is associated with a 0.5% risk of death. Some short term side effects can occur and the most serious one although very rare is a stroke. Unilateral deafness can occur in up to 2% of patients. Numbness is very rare. There is good evidence to show that complications are less likely to occur if the procedure is done by neurosurgeons who specialise in this operation.
- *Rhizotomy* – if no compression is found at surgery the surgeon may partially cut the nerve but it does result in loss of sensation on one side of the face and the other complications are as above.

Radiosurgery

Gamma knife surgery

This is a very new procedure and as yet there are no long term results. This procedure aims to damage part of the trigeminal nerve inside the brain. Using the MRI and special equipment, a beam of radiation is directed at the nerve. No surgery is involved so it can be done as day case surgery. Pain relief often does not occur immediately and it may be three months before complete pain relief is obtained. Pain relief is probably in the order of years. There are a very limited number of centres who do this in the UK at present.

Deciding on treatment

Your neurosurgeon, pain specialist or neurologist will help you decide if the risks of surgical procedure are fewer than the risks of leaving the condition untreated. It is not easy to make a decision and everybody needs to make their own decision after gathering as much information as possible. Not only is pain relief important but also your quality of life. You may find it helpful to speak to other patients as you may feel that you are the only person with this condition. It may be helpful to ask someone else to come with you to the consultation to ensure you have asked all the relevant questions and got the answers.

What support is there for patients?

There are support groups in the UK and US who can answer many of your questions and put you in touch with other patients. A very helpful book has been written by a patient and neurosurgeon called *Striking Back* by George Weigel and Ken Casey (ISBN 0-9672393-0-3) it is available through the US Trigeminal Neuralgia Association PO Box 340 Barnegat Light NJ 08006 USA or web site <http://www.tna-support.org> Cost \$13.95 around £12.

The Brain and Spine Foundation UK have also published a booklet on facial pain that includes details on trigeminal neuralgia, 7 Winchester House, Kennington Park, London SW9 6EJ.

The UK has established a support group and has its web site. <http://www.tna-uk.org.uk/>.

The UK contact is Mrs Carole Straker, PO Box 413, Bromley, Kent BR2 9EP, tel 020 8462 9122, email carole.staker@ukgateway.net.