

Patient leaflets from the BMJ Group

Trigeminal neuralgia

Trigeminal neuralgia is a very painful condition affecting the face. There is no cure but there are lots of treatments that may help.

We've looked at the best and most up-to-date research to produce this information. You can use it to talk to your doctor and decide which treatments are right for you.

What is trigeminal neuralgia?

If you have trigeminal neuralgia, you get sudden, short attacks of bad pain in your face. They usually affect just one side of your face, and they keep coming back. The pain comes from the trigeminal nerve, which carries feelings from your face to your brain.

Women, people aged over 50, and people with high blood pressure are more likely to get trigeminal neuralgia.

We don't know exactly what causes trigeminal neuralgia. Some doctors think it is caused by blood vessels pressing on the trigeminal nerve.

What are the symptoms?

Trigeminal neuralgia is very painful. You get a sudden, severe, stabbing pain. Some people describe it as feeling like an electric shock.

Most people feel pain in or around the cheek or jaw areas. This can include the lower eyelids, nostrils, lips and gums. Some people feel pain around the eye or forehead, but this is less common.

The pain can last from a few seconds to a couple of minutes at a time. It usually affects just one side of your face.

Attacks of pain can come on without warning. But they can be triggered by talking, eating and drinking, cleaning your teeth, brushing your hair, shaving, facing into the wind, or other actions.

Your attacks may come one right after another, or come and go. You might have a series of painful attacks lasting for weeks. Or they might go away for a long time.

There is no test for trigeminal neuralgia. Your doctor will examine your face and ask you questions about your pain. You may need to be checked for other conditions.

If your doctor is not sure about the diagnosis, you may need to go to hospital for an MRI (magnetic resonance imaging) scan. This can show whether you have blood vessels pressing on the root of your trigeminal nerve. An MRI scan can also rule out a more serious cause for your pain.

What treatments work?

There are lots of different treatments for trigeminal neuralgia. But there's not a lot of research to show which treatments work best. You'll probably be offered medicine first. If that doesn't work you may need an operation.

Medicines

Carbamazepine gives good pain relief for trigeminal neuralgia. Carbamazepine (brand names Carbagen, Tegretol) is usually used to treat epilepsy. But it can also be used for trigeminal neuralgia. Most doctors think carbamazepine is the first treatment to try for trigeminal neuralgia. You normally start on a low dose and build up gradually until you find the dose that best treats the pain. You then have to take it regularly.

About 6 in 10 people get good pain relief from carbamazepine. But between 2 in 10 to 5 in 10 people also get side effects. The most common ones are drowsiness, dizziness and constipation. Some people get other, less common side effects from carbamazepine. These include skin rashes, changes in blood cells and problems with how their liver works. Carbamazepine can decrease the number of blood cells produced by your body. Very rarely, the blood cells are affected enough to cause serious health problems.

Carbamazepine may stop working after a while. One study found that only about one-third of people still found the drug worked well several years after starting it.

Some other medicines used for epilepsy are also tried for trigeminal neuralgia. These include lamotrigine, phenytoin, clonazepam, sodium valproate, gabapentin, oxcarbazepine and topiramate. But there hasn't been any good research to show whether they work.

Oxcarbazepine is often used if you get bad side effects from carbamazepine.

Many other medicines of other types are also tried. These include two medicines to relax the muscles, called baclofen (Baclospas) and tizanidine (Zanaflex). There hasn't been any good research to show whether they work.

Things you can do for yourself

You may notice certain things that trigger an attack of pain, like eating or being exposed to the wind. There may be some things you can do to avoid these triggers. But there's no research to say whether they will help.

You could:

- Avoid sitting in the direct blast of an air conditioning unit
- Protect your face with a scarf when you go out in cold weather
- Avoid very hot or very cold drinks or food
- Use a drinking straw. This can help you avoid getting a hot or cold drink on the area of your mouth that causes pain
- Use pain-free periods to eat and take any necessary medications during a flare-up, to keep as well as possible

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- Ask your doctor for help if you feel depressed. It's not surprising that many people who have long-lasting painful conditions get depressed. But there are some good treatments for depression that can help.

Surgery

An operation called **microvascular decompression** is likely to work. It's the standard operation for trigeminal neuralgia. Research shows it works well for many people. The surgeon stops blood vessels pressing on the root of the trigeminal nerve. In a long-term study, 7 in 10 people were free of pain and didn't need medication, ten years after the operation.

But microvascular decompression is a major operation. Some people get problems (complications) from the operation, although these don't happen very often. These include losing the hearing in one ear, weak face muscles, numbness in the face and double vision. In one study, 16 out of 1,000 people lost the hearing on the affected side of their face. More seriously, a few people have strokes or die after the operation.

There hasn't been enough good-quality research to say for sure whether other operations work. But we've included information about some of them, as you may have questions.

Stereotactic radiosurgery uses radiotherapy to deaden the nerve. If you have a nerve block, the doctor injects a local anaesthetic near the nerve, to block pain. Injections are usually repeated several times over weeks or months. Some people find the injections painful.

If you have **cryotherapy**, the surgeon will cut through the skin to the trigeminal nerve, then use chemicals to freeze the nerve. It relieves pain for only a few months. If you have **laser treatment** the doctor will use the laser on the skin of your face that's over the trigeminal nerve.

All these operations carry risks. Doctors use a variety of methods to cut or damage the trigeminal nerve, to try to stop it from sending the pain messages to your brain. You can ask your specialist about the different options, how well they are likely to work for you, and what your chances are of getting complications.

What will happen to me?

You may have long periods free of pain. But as you get older, trigeminal neuralgia attacks can get more frequent and more painful. The pain-free intervals can become shorter And some people get a background pain all the time.

Where to get more help

The Trigeminal Neuralgia Association UK is a UK charity providing information and support to people living with trigeminal neuralgia. You can contact them at <http://www.tna.org.uk>.

Trigeminal neuralgia

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