

Face pain



Brain & Spine
Foundation

The Brain & Spine Foundation provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions – patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information, and by answering the common questions that people ask. Any medical information is evidence based and accounts for current best practice guidelines and standards of care.

Contents

| | |
|-------------------------------|----|
| Common questions..... | 2 |
| Trigeminal neuralgia..... | 3 |
| Tests and investigations..... | 7 |
| Possible treatments..... | 8 |
| Other types of face pain..... | 20 |
| Pain management..... | 28 |
| Useful contacts..... | 30 |
| Support groups..... | 33 |
| Further reading..... | 33 |
| Pain diary..... | 34 |
| References..... | 36 |
| Thank you..... | 36 |

Introduction

This booklet provides information on face pain in adults. It focuses on persistent, non-dental face pain. The booklet describes different types of persistent face pain and provides information on common symptoms, tests and investigations and possible treatments. Sources of further support and information are listed in the [Useful contacts](#) section. References are available on request.

Common questions

What is persistent (chronic) pain?

Persistent pain (also known as chronic pain) is long-term pain that has lasted more than three months. People can feel persistent pain anywhere in their body including the mouth or face. Very often there are no visible signs or causes.

What is persistent face pain?

People with persistent face pain experience pain because of changes to the way the nerves in the face transmit signals to the brain, which are then interpreted as pain. The nerves can become extremely sensitive and the signals going up the brain do not switch off the way they should. Unlike other types of pain, this ongoing pain is not due to infections or injuries, even if an infection or injury was the cause of the initial pain. The signals are transmitted to the brain and are affected by a variety of factors including mood, thoughts and activities.

How can persistent face pain affect everyday life?

Persistent face pain affects many different aspects of people's lives. It can make everyday life difficult to manage, affect people's mood and cause unhappiness and depression.

Each person with persistent face pain is affected differently but common problems include

- stopping or cutting back on enjoyable activities
- disturbed sleep
- finding it hard to speak or have conversations and socialise
- worrying about the future
- losing self-confidence
- feeling more worried, angry, irritable or low in mood.

Trigeminal neuralgia

What is trigeminal neuralgia?

'Trigeminal' is the name of the particular nerve affected and 'neuralgia' is the medical term for nerve ('neur-') pain ('-algia').

People with trigeminal neuralgia experience sudden attacks of pain on one side of their face. The pain comes and goes suddenly and is intermittent. Some people may have long periods of time (months or even years) free from pain, known as remission periods. Other people may experience frequent attacks of pain with multiple attacks a day (sometimes even hundreds). Trigeminal neuralgia very rarely affects both sides of the face and, even then, rarely at the same time.



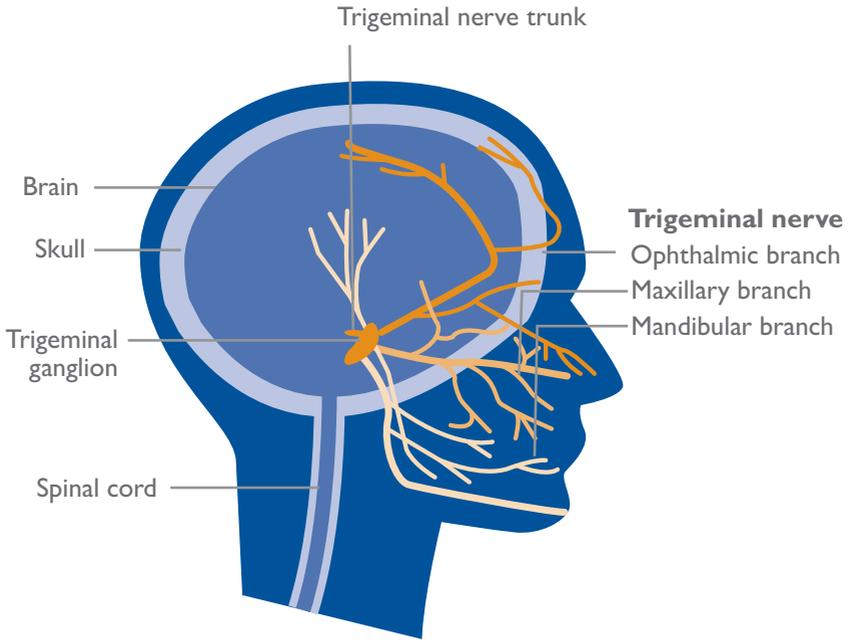
Who gets trigeminal neuralgia?

Trigeminal neuralgia can affect people of any age but it is very rare in children. It is more common in older people and less common in younger adults. Women are affected more commonly than men.

How common is trigeminal neuralgia?

Trigeminal neuralgia is rare. It is thought that there could be around 50,000 people with the condition in the UK.

Nerves and structures in the head that are involved in trigeminal neuralgia



The **trigeminal nerve** is the largest of the cranial nerves (nerves inside the head). There are two trigeminal nerves, one on the left side of the head and one on the right side. Each nerve has three branches (hence 'tri-'). The first branch is responsible for sensation in the forehead (ophthalmic branch), the second for the cheek (maxillary branch), and the third for the jaw and the temple region (mandibular branch). Doctors sometimes call these branches 'divisions'.

The two trigeminal nerves transmit information about temperature, pressure and chemical changes from each side of the face to the brain. They also control the muscles involved in chewing and equalising pressure in the ears, but they do not affect the muscles of facial expression.

What causes trigeminal neuralgia?

We do not know the exact cause of trigeminal neuralgia. However, evidence suggests that the problem lies within the brain, in the nerves inside the head or in the trigeminal nerve as it passes through the face. It is thought the way the nerve transmits information is at fault.

In most cases, doctors believe the pain comes from a blood vessel pressing on the trigeminal nerve where it enters the brain (an area called the 'root entry zone'). This is known as vascular compression ('vascular' refers to blood vessels). The pressure from the blood vessel damages the protective outer coating of the nerve (the myelin sheath) and the nerve becomes very sensitive. This results in the brain receiving signals from the nerve that are felt as pain, usually for no apparent reason.

Very rarely, trigeminal neuralgia can be caused by a cyst (a fluid-filled sac), an arteriovenous malformation (an abnormal tangle of blood vessels) or a tumour (usually non-cancerous) pressing on the nerve. People with multiple sclerosis (MS) are at higher risk of experiencing trigeminal neuralgia and in a small percentage of patients it can be their first symptom. These other causes are relatively easy to rule out by investigations, such as an MRI scan.

What are the symptoms of trigeminal neuralgia?

People with trigeminal neuralgia might feel pain on the skin on their face or in their mouth and teeth. The pain can come and go suddenly and unpredictably. People often use words like stabbing, shooting and electric shock-like to describe the pain.

Each burst of pain lasts just a few seconds or minutes but some people might experience several bursts one after another, and this can last for hours. These more prolonged attacks can become extremely debilitating. For some people, the pain can continue as a burning or aching feeling that lasts for some time after the main

attack of sharp pain. This dull, background type of pain often results in people being told they have what could be termed 'atypical trigeminal neuralgia', 'trigeminal neuralgia with concomitant pain' or 'type 2 trigeminal neuralgia'. Doctors still do not know if this is the same condition or whether it is a sign of the progression of trigeminal neuralgia. It may also be due to a lack of muscle use on the painful side of the face.

The pain commonly affects the jaw and cheek but it might affect the whole side of the face. People often have 'trigger points' on their skin which bring on a sudden spasm of pain when touched. Various light touch activities can bring on the pain, such as cleaning the teeth, washing the face, shaving, putting on makeup, eating, talking, laughing or smiling. The wind, a light breeze or air conditioning can also trigger attacks. Attacks can also occur without any trigger. This is called spontaneous pain.

People might experience pain everyday for weeks or months only for it to disappear for a period of time (months or even years). However, over time, attacks can become more frequent, longer-lasting and more intense. There is no way of predicting when the pain will come and go. Between attacks many people can be very fearful about when the pain may return.

There are two other conditions known as **short unilateral neuralgiform headache with autonomic symptoms (SUNA)** and **short unilateral neuralgiform headache with conjunctival redness and tearing (SUNCT)** which produce similar symptoms to trigeminal neuralgia. During an attack, people with these conditions experience pain often with physical symptoms on one side of their face, such as redness of the eye and face, a runny nose, tears and a drooping eyelid. It may be that these are variations of trigeminal neuralgia, as sometimes symptoms occur with each attack and at other times only with the longer attacks. People with SUNA and SUNCT often have longer pain attacks, more attacks per day and fewer pain-free periods.

Tests and investigations

Trigeminal neuralgia can be a difficult condition to diagnose because each person is affected differently and the pain can feel different for each person. Many people visit their dentist when they first experience symptoms because it feels as if the pain is coming from a tooth or teeth. They may have lots of dental treatment before they are diagnosed with trigeminal neuralgia.

Trigeminal neuralgia cannot be diagnosed by any specific tests. Doctors rely on accurate descriptions of the symptoms and careful, thorough examinations. It is very important to keep notes about the pain you are experiencing: its frequency, the length of attacks, severity, location, factors that affect it, and any other features you notice (see pain diary example on pages 34-35).

It is important for other possible causes of face and mouth pain to be ruled out. These include problems with the teeth, mouth, ears, skull and the glands around the mouth and the face, so doctors will examine these areas thoroughly.

After being assessed, you might have a scan of your brain. This is to check that there is not a tumour or other abnormality putting pressure on the nerve. A special, so-called 'thin cut' MRI scan might be able to show if any blood vessels are touching or pressing on the nerve.

Possible treatments

Medication



Pain relief drugs, such as paracetamol, aspirin or ibuprofen, do not usually help people with trigeminal neuralgia.

Anticonvulsants (anti-seizure drugs) are the group of drugs most commonly used to treat trigeminal neuralgia. These drugs are also used to treat epilepsy. They work by reducing the activity of the nerves. They do not cure trigeminal neuralgia but they can reduce the level of pain people experience. It is important to note that these drugs cannot be taken in the same way as painkillers. Anticonvulsant drugs need to be started at a low dose and very slowly increased to build up to the best dose for the individual's pain control. The possible side effects of anticonvulsants include drowsiness, fatigue (extreme tiredness) and difficulty concentrating. In higher doses, the possible side effects include balance problems, memory problems and double vision.

Carbamazepine (brand name Tegretol) is an anticonvulsant drug. It is the first choice of drug for treating trigeminal neuralgia in the UK.

The possible side effects can be quite severe, especially in higher doses, however it is an effective treatment for 75% of people. Around 7% of people (seven people in every 100) who take it develop a rash. This is particularly likely to happen in Han Chinese and Thai people. If this happens you should stop taking the drug immediately and seek advice from your doctor. Carbamazepine can also interfere with how other drugs work so you should tell your doctors about any other medication you are taking. You will need regular blood tests when you first start taking carbamazepine, and these regular tests should be continued especially if you are taking a high dose. You might need to take an increased dose over time. Some people do not take the full dose because of the side effects; it is a case of finding an acceptable balance for each individual.

Oxcarbazepine is an alternative drug to carbamazepine. It is similar but has fewer possible side effects and does not interfere with other drugs as much. Again, you will need to have regular blood tests with this drug, especially if you are taking a higher dose.

Other anticonvulsant drugs can be prescribed instead of carbamazepine or oxcarbazepine. They might not always be as effective but they can be useful for people who cannot take carbamazepine.

You might be prescribed drugs used to treat neuropathic pain (nerve pain), for example, gabapentin (brand name Neurontin) or pregabalin (brand name Lyrica). However, there is limited evidence that these drugs are effective in treating trigeminal neuralgia.

Baclofen is a muscle-relaxing drug often given to people with multiple sclerosis. It can also be prescribed for people with trigeminal neuralgia. It is usually combined with an anticonvulsant drug and can be effective in the early stages of the condition for some people. However there is a lack of evidence to prove how effective this treatment is.

Lamotrigine can be given to people with trigeminal neuralgia who cannot take carbamazepine. It is sometimes given in addition to

carbamazepine, if carbamazepine becomes less effective over time. It needs to be started at a very low dose and gradually increased to control side effects, such as a rash. This drug seems to be particularly helpful in patients with SUNA and SUNCT (see page 6), although there is only limited evidence to prove this.

Some of the drugs are taken only twice a day whereas others sometimes need to be taken four times a day to ensure the drug level in the blood is enough to reduce pain. Women tend to get more side effects than men. For men or women, the dosage of all these drugs can be increased over time if the pain becomes more severe. It may also be useful to use a combination of drugs. It is essential that any drug is taken exactly as it has been prescribed by a health care professional and that the amount taken does not exceed the prescribed dose.

Some recent studies are suggesting that botulinum toxin (Botox) injected into 'trigger points' on the face can be helpful. Services that deal with migraines may be able to give these injections.

Local anaesthetic injections (lidocaine) might be helpful when people experience persistent severe attacks. These injections can be given several times and can be more effective than morphine. In extreme cases the drug can be given through a vein.

If your face pain disappears for several months the drugs you are taking should be slowly withdrawn. They should only be restarted if the pain returns. Many people find it helpful to keep a record of changes in their pain levels and the particular drugs and doses they are taking at the time. A good way to do this is to keep a pain diary with dates, a rating of the severity of your pain (for example, on a 0 to 5 scale), how the pain has affected your everyday activities (on a 0 to 5 scale), the drugs you are taking and any side effects you are experiencing (an example can be found on pages 34-35). Your doctor or specialist will also find this information useful, so take it with you to each appointment.

Surgery and stereotactic radiosurgery

Drugs are the best form of treatment for trigeminal neuralgia, if they are acceptably controlling the pain. However, if drugs fail to relieve the pain, cause unmanageable side effects or impact too much on your quality of life, you might wish to consider other options – if they have been offered by a doctor – such as stereotactic radiosurgery or surgery. It is important that you discuss the options with your specialist or a neurosurgeon in the early stages of trigeminal neuralgia and have all your questions answered.

Operations to treat face pain are mainly performed by a neurosurgeon – a specialist doctor who carries out surgery on the brain and spine (neurosurgery). A radiographer will be involved if you are having radiosurgery. Some of the procedures can be carried out by doctors who specialise in pain management.

Microvascular decompression of the nerve (MVD)

Microvascular decompression involves a surgical procedure. Under a general anaesthetic, the neurosurgeon makes an opening at the base of skull behind the ear. The neurosurgeon then gently moves the blood vessel(s) pressing on the trigeminal nerve where it emerges from the brain stem. An artificial pad will then be used to protect the nerve from being compressed again by the blood vessel(s). Having an MVD involves a hospital stay of three to five days. The time it takes to recover from the procedure will depend on a patient's age and fitness. Most people recover fully within six weeks, however for some people it can take much longer (anything from six months to a year).

Because microvascular decompression avoids damaging the trigeminal nerve, there is a very low risk of facial numbness following the surgery. Most people experience immediate pain relief with this procedure, and there is evidence to show that around 70% of people (seven people in every 10) are still free of face pain 10 years afterwards.

The main disadvantage of this procedure is that it involves operating on an important part of the brain and so does carry a very small risk of serious complications. It is possible that the nearby nerves coming from the brain stem can be damaged during the procedure. These include the nerves involved in hearing and balance and so a small number of people experience hearing loss (less than 5% of cases or five people in every 100) and balance problems after the surgery. More rarely, people can experience weakness in the face (on the side of the operation), difficulties with swallowing or double vision. Some people find that these problems can improve over the months following the surgery. There is also a very small risk of stroke following surgery and even death in approximately 0.5% of cases (one person in every 200).

Some people experience pain around the wound behind the ear or numbness in the ear. This usually improves but it might go on for several months. There is a very slight risk that a patient may experience facial numbness following surgery and an even lower risk they may develop a condition called '**anaesthesia dolorosa**'. Anaesthesia dolorosa is a severe, dull, continuous pain in the numb area of the face. There is currently no cure for this condition.

The most common complication of the procedure is cerebrospinal fluid (also known as CSF, the liquid that surrounds the brain and spine) leaking from the nose, ear or the wound itself. It can occur up to about a week or so following the operation. If this happens, the neurosurgeon must be notified immediately so that the leak can be stopped to prevent germs getting into the skull and causing meningitis. Sometimes another small operation might be needed.

Stereotactic radiosurgery

Stereotactic radiosurgery is a type of radiotherapy and a newer treatment for trigeminal neuralgia. It is only available in a few specialised neurological centres in the UK. Despite its name, the treatment is not a surgical procedure and does not involve any incisions (cuts). It works by deliberately damaging the trigeminal nerve with high energy beams of radiation directed at a point just behind the ganglion. The Gasserian ganglion (or trigeminal ganglion) is just inside the base of the skull. It is a group of nerve cells the size and shape of a split broad bean. It is the point where all the branches of the trigeminal nerve meet (see diagram on page 4).

Radiosurgery is delivered by very specialist machine equipment (Gamma Knife, CyberKnife or LINAC). Patients are fitted with a special metal frame to keep their head still. The treatment can take a few hours and an overnight stay in hospital might be needed.

Early research results suggest that stereotactic radiosurgery offers similar rates of pain relief to other procedures that 'interrupt' the nerve (see page 14). A disadvantage of stereotactic radiosurgery is that pain relief can be delayed for a few months and patients might experience areas of numbness up to six months after the treatment. A very small minority of people might develop anaesthesia dolorosa.

Interrupting the nerve ('ablative' or 'destructive' procedures)

There are several ways to interrupt or block activity in the trigeminal nerve. These procedures can relieve the pain but nearly always leave an area of numbness in the face because they involve destroying part of the nerve. The nerve can be interrupted at one of three sites.

(You might like to refer to the diagram on page 4.)

1. The ganglion

To reach the ganglion, the surgeon inserts a needle through the cheek into a small hole in the base of the skull. X-ray equipment is used to guide the needle. The surgeon injects the ganglion with **glycerol** or applies heat to it (**thermocoagulation**). This causes damage to the ganglion which stops it from passing on signals from the face to the brain. Alternatively, the surgeon or specialist might compress the trigeminal nerve with a tiny inflatable balloon positioned at the tip of the needle (**balloon compression**).

Procedures to interrupt the trigeminal nerve at the ganglion are usually carried out with the patient under heavy sedation and partially awake. This is so the surgeon can make sure the needle is in the correct place by checking the patient's responses to stimulation. An overnight stay in hospital might be required for these procedures.

Unfortunately, the majority of people having this surgery will be left with an area of numbness on their face. People often describe the feeling as similar to a dental injection wearing off, but the sensation can be permanent. It is impossible to predict the extent of loss of sensation. A small number of people experience anaesthesia dolorosa after the surgery (see page 12).

There are other possible risks with the techniques used to interrupt the nerve at the ganglion. People should consider these carefully before deciding to go ahead with the surgery. Because the needle goes into the skull, there is a chance of complications affecting the brain. There is a very small risk of people experiencing complications such as meningitis, brain abscesses, brain haemorrhages (bleeds) or

heart attacks following the surgery. These are serious complications and can result in permanent cognitive and physical disabilities or, in very rare cases, even death.

Sometimes it is difficult for the surgeon to position the needle into the part of the nerve which goes to the forehead. So, for people who experience trigeminal neuralgia mainly in their forehead, a large area of numbness might be created before any pain is relieved. Unfortunately, some of these people find they lose or have a reduced blink reflex. This means that they cannot feel anything touching the eye, which creates a risk of further problems if the eye ever becomes scratched or infected.

Some people experience difficulties with eating for a few months after the surgery, most often after balloon compression.

Most people do not find the procedures to interrupt the nerve at the ganglion too uncomfortable but for some they can be an extremely unpleasant experience. Many people are prepared to have the procedure again if the pain returns.

Pain relief can last between two to four years without the need for any medications.

2. The outside of the face

The small branches ('peripheral' branches) of the trigeminal nerve inside the mouth and forehead might be cut (neurectomy), frozen (cryotherapy) or lasered. The surgeon can usually carry out these procedures under a local anaesthetic. This means that the area will be numbed and you will be awake throughout the procedure. People might be left with a small area of numbness on their face. Unfortunately, the pain is often only reduced for around 10 months. These treatments are rarely done now that other more effective treatment options are available. Interrupting the nerve on the outside of the face is usually only recommended when other treatments are not possible.

Evidence is starting to emerge to show that injections of botulinum toxin A (Botox) into ‘trigger points’ on the face might be helpful for some patients. Services that deal with migraines may be able to give these injections.

3. The nerve trunk

The nerve trunk is the section of the trigeminal nerve between the brain and the ganglion. The procedure to interrupt the nerve at this point is called a **partial sensory rhizotomy (PSR)**. It is less common than it used to be and is now carried out on relatively few people. A variation of this procedure is internal neurectomy (IN) which involves ‘combing’ the nerve.

Under a general anaesthetic, the surgeon makes an opening at the base of the skull just behind the ear. The surgeon then cuts, crushes or divides part of the trigeminal nerve which is responsible for sensation (feeling) in the parts of the face affected by pain. People often experience areas of numbness after this procedure.

Pain relief with no need for medications can last for many years.

The possible complications of PSR are the same as those of microvascular decompression ([see page 11](#)). However, it is important to note that the risk of numbness is much higher for PSR as the procedure always involves deliberately damaging the trigeminal nerve.

Neurostimulation

Attempts have been made to treat trigeminal neuralgia and other forms of persistent face pain with neurostimulation. A variety of methods have been used to apply this technique. All involve placing an electrode on to the trigeminal nerve or ganglion.

Neurostimulation does not provide a cure for trigeminal neuralgia. Neurostimulation is not suitable for everyone and it is only used for a small number of people with persistent face pain for whom it might provide some benefits. To receive neurostimulation, you will need to be referred to an expert in the treatment. You can discuss your options with your doctors. Currently, there is no evidence to prove that it is effective in treating face pain.

Complementary treatments

Some patients have found that certain complementary treatments and therapies offer them some relief from their face pain. Whilst there is no evidence to support their effectiveness, some patients claim to have found pain relief from vitamin B12, low light therapy, capsaicin cream and chiropractic treatment. It is very important that you always speak to your doctor before trying any complementary treatments to be sure that it is safe for you to do so.



Who makes the decisions about my treatment?

If your face pain is controlled by drugs this is likely to be the best form of treatment for you personally. However, if the pain is not controlled by drugs or you experience unmanageable side effects, you might need to consider carefully the surgical treatment options that might be available to you. You should discuss the options with your medical and surgical team and be involved in any decisions about your treatment. You should be offered more than one surgical option. Further support and information is available from patient support groups (see page 33).

Once you are clear about the potential benefits and risks of different surgical treatments, you will need to weigh them up and decide whether the risks are worth taking. This will differ for individuals. You should bear in mind the likely success of the different options, how long the benefits might last and what the specific risks might be. *The Ottawa Personal Decision Guide* might be a helpful resource (see the Further reading section).

Currently, most specialists believe that for healthy people microvascular decompression (MVD) is likely to be the best surgical option (see page 11). For most people, this procedure provides lasting pain relief without numbness. For people with other health problems, those who cannot afford the time off work and those who choose not to take the risks associated with microvascular decompression, the usual recommendation is to treat trigeminal neuralgia by interrupting the nerve at the ganglion. Relief from the pain will not last as long and there might be areas of numbness. However, procedures to interrupt the nerve at the ganglion can be repeated and different surgical treatments remain an option for the future. Microvascular surgery can sometimes also be repeated. Stereotactic radiosurgery might be an option for people who cannot undergo surgery for medical reasons.

All of these factors need to be carefully considered by people deciding which treatment options are right for them. No one should feel under pressure to have a particular treatment if they do not want it. You should bear in mind that not all the options will be available at the hospital where you receive your initial treatment. Also, not all the available treatments will be helpful for you, so your doctors might not offer them to you.



Other types of face pain

Glossopharyngeal neuralgia

Glossopharyngeal neuralgia is a rare condition that is sometimes confused with trigeminal neuralgia. The pain is equally severe and affects one side of the head. It is usually felt at the back of the tongue and the back of the throat. It might also start at, or move to, the ear. These areas become oversensitive (or hypersensitive). The pain can be triggered by touching the ear or swallowing.

Doctors use the same methods to diagnose glossopharyngeal neuralgia as they use for trigeminal neuralgia. The drugs used to treat it are also the same.

Post-herpetic neuralgia

Post-herpetic neuralgia is a form of persistent pain after an attack of shingles. Pain can affect any part of the body that was affected by shingles, including the face. The type of pain that occurs with post-herpetic neuralgia is called neuropathic pain because it involves the nerves.

People with post-herpetic neuralgia usually experience a burning, aching or throbbing pain that is often accompanied by extreme tenderness. They might find that the wind blowing against their face or the brush of clothing or bedclothes is unbearable. Although people experience extreme tenderness in the affected areas, the general sensitivity of their skin may be reduced.

What is shingles?

The medical name for shingles is herpes zoster. Shingles is caused by the chickenpox virus which most people get as a child. Shingles usually affects older people. It occurs when the virus, which has been in the body for many years without causing any symptoms, begins

to flare up again and attacks one of the nerves in the skin. It most commonly affects a nerve on the upper body but it can affect nerves in the head and face. It only ever affects one side of the face.

Shingles can begin with a dull pain or a burning or tingling sensation in the skin. For most people, this is followed a few days later by a weeping rash. The rash usually clears up within a few weeks. This can be helped by certain drugs, such as acyclovir. Some people are left with scarring but the majority of people find that the pain settles down and the rash disappears without leaving any scars.

How does shingles cause post-herpetic neuralgia?

The virus damages the nerve and so the area of skin served by that nerve goes partly numb. People may experience pain in this area. The pain happens because the nerve continues to send signals to the brain that result in pain.

Who gets post-herpetic neuralgia?

Anyone who has had shingles can get post-herpetic neuralgia, although it is very rare in younger adults. Post-herpetic neuralgia mainly occurs in people aged 65 years and older. Approximately one in five people who have shingles will continue to experience pain after the rash has healed. Only a small number of these people will develop the condition in the face.

What are the treatments for post-herpetic neuralgia?

If people are still experiencing face pain a month after the shingles rash has disappeared their GP may prescribe medication. This is because medication is more effective when it is taken in the early stages of post-herpetic neuralgia. Ordinary pain relief drugs usually have very little effect on post-herpetic neuralgia.

The main drugs used to treat post-herpetic neuralgia are gabapentin, amitriptyline or nortriptyline. These drugs have been used to treat depression and epilepsy but they can have a very powerful effect on

Other types of face pain

certain forms of nerve pain. It might take two to three weeks before they begin to provide any pain reduction. People might be given a low dose to start with that is gradually increased, and may need to take these drugs for several months.

Other medicines prescribed to treat post-herpetic neuralgia include the anticonvulsants gabapentin and pregabalin. Some people find creams, lotions and patches helpful. These act as local anaesthetics and numb the area. The patches (e.g. Versatis) contain an anaesthetic (for example, lidocaine) and can be applied for 12 hours at a time. The patches look like plasters.

Surgical procedures to interrupt the nerve (used to treat people with trigeminal neuralgia) are never effective in the treatment of post-herpetic neuralgia.



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Temporomandibular disorders (TMDs)

Temporomandibular disorders (TMDs) are known by several different names, including 'facial arthromyalgia'. The temporomandibular joint is the hinge joint in the jaw. Within the joint is a small disc that moves with the lower jaw. Most people with TMDs have problems with the muscles in their jaw rather than the joint itself. It can be helpful to think of TMDs as cramp in the muscles.

What are the symptoms of TMDs?

The main symptoms of TMDs are

- pain, discomfort and tenderness around the ear and surrounding muscles, either on one side or both
- dull, aching pain (but sometimes the pain is sudden and sharp)
- jaw locking when you open your mouth and reduced opening of your mouth, though this is less common
- clicking noises coming from one or both joints in the jaw when you open or close your mouth. (These noises are because the way the disc moves is altered. They do not necessarily mean that the jaw bone is damaged.)

Other symptoms include

- earache, buzzing in the ear or a blocked sensation in the ear
- headache and migraine
- neck ache
- pain in other parts of the body (for example, backache)
- disturbed sleep.

What causes TMDs?

Different causes for TMDs have been suggested. These include hereditary factors, genetic increased sensitivity to pain and previous injuries to the jaw joint and muscles. Except for people with arthritis in the jaw (which is rare and often not painful), it is unusual for there to be damage to the bone in the temporomandibular joint. Stress does not cause TMDs but it can increase the levels of pain people experience.

Experiencing pain and stiffness in the jaw can be worrying. Some people might worry that their jaw is damaged, that the pain will worsen or that their jaw might lock. It is important to know that TMDs are rarely the result of serious disease.

What are the treatments for TMDs?

Dentists often recommend that people use splints at night. Splints are devices that cover some or all of the teeth and might be helpful for people who clench or grind their teeth to such an extent they begin to damage them. However, there is not enough evidence to suggest that they are essential for people with TMDs. Splints might cause distress and poor sleep because they can be bulky.

People with TMDs might experience a few days or weeks with severe pain and difficulty opening their mouths. During this time, there are a number of things that can help people with managing their pain.

- Eat a soft food diet and use both sides of the mouth at the same time, or alternate sides, when eating. Try to return to a normal diet when the pain improves. Staying on a soft food diet will mean that you are not using the muscles in your jaw which can result in more stiffness and pain.
- Chew with the back teeth rather than biting with the front teeth.
- Avoid opening the mouth widely (for example, to yawn or to have dental treatment) until the pain has settled. Once the pain has settled, you can return to opening your mouth widely as you would do normally.
- Avoid habits that put strain on the jaw muscles and joints (for example, chewing objects or clenching the jaw).
- Apply a warm or cold face towel (whichever feels better) for 10-20 minutes, three or four times a day.
- Keep the tongue in the roof of the mouth and the top and bottom teeth apart. This keeps the jaw muscles in a relaxed position.
- Take pain relief medication (as long as there is no medical reason to avoid it).
- Learn and regularly practise relaxation techniques (for example abdominal breathing or mindfulness).

Persistent idiopathic facial pain (atypical facial pain)

The name 'atypical facial pain' has been used in the past but, as nobody has been able to define 'typical' facial pain, this is no longer considered an appropriate term. This is now called either persistent idiopathic facial pain or chronic idiopathic facial pain. To be given this name, the face pain must have lasted for more than three months, have no identifiable cause and not respond to usual pain relief medications. Persistent idiopathic facial pain can come and go or it can be continuous. It varies in intensity and can last for many years. It might affect a small part of the face or the whole of the face and mouth. People often describe the pain as nagging, throbbing or aching.

Persistent idiopathic facial pain is often experienced by people who have pain in other parts of the body, such as the pain caused by irritable bowel syndrome. It can also be experienced by people with itchy skin.

Stress does not cause chronic idiopathic facial pain but it can make the pain worse. People might experience increased pain during times of change or difficult times in their lives, such as moving house, changing jobs or a relationship breaking up.

There are no tests available to help diagnose persistent idiopathic facial pain so doctors rely on people offering accurate and specific descriptions of their symptoms.



Atypical odontalgia (trigeminal neuropathic pain or persistent dento-alveolar pain disorder)

Odontalgia is the medical word for toothache. 'Atypical' means that the pain is not caused by dental problems, which would be the usual or 'typical' cause. People with atypical odontalgia experience a dull ache or severe discomfort in one or more of their teeth or in their gums where they previously had teeth. It can start after dental treatment such as a filling, root canal treatment or having a tooth extracted. The pain might move from one tooth to another. Touching the affected area can worsen the pain. Some people describe the pain as a burning pain or pins and needles.

Atypical odontalgia is not caused by problems with the teeth or gums, even though it may feel like this. Dental treatment or tooth removal will not stop the pain. It is a nerve-type pain (neuropathic) and, as with many types of face pain, it is the nerve signal mechanism that has become faulty.

Burning mouth syndrome

Burning mouth syndrome (BMS) is the name for a condition that causes a burning sensation or changes in the sensation in the tongue or other parts of the mouth. People with burning mouth syndrome might experience an unpleasant taste in their mouth or a feeling that they have too much or too little saliva. They might also feel some numbness in the mouth. Dentures, crowns and bridges might become so uncomfortable that it is impossible for people to wear them, even after adjustments. Burning mouth syndrome mainly affects women around the menopause but it can affect men and women of any age.

It is thought that burning mouth syndrome is a type of neuropathic pain caused by damage to the small nerves supplying the tongue and mouth. Studies have shown that the nerves are not transmitting information correctly.

There is no specific test to check for this condition but some people will have a burning sensation which is caused by other factors. For this reason, a dental or medical specialist will carry out a thorough examination of the mouth to rule out other possible causes of discomfort, such as thrush (a yeast infection also known as candida). They will also check whether any drugs or medication currently being taken could be the cause. Blood tests might be carried out to check for conditions such as diabetes, anaemia and vitamin deficiencies.

What are the treatments for persistent idiopathic facial pain, atypical odontalgia and burning mouth syndrome?

There are no surgical treatments for these conditions. The treatments used are medication and developing ways to manage the pain (see [Pain management section](#)).

Pain relief drugs such as paracetamol, aspirin or ibuprofen do not usually help people with persistent face pain. People are often prescribed antidepressant or anticonvulsant (anti-seizure) medication. Being prescribed antidepressants does not mean that someone thinks the person with pain is depressed. Research has shown that some anticonvulsants and antidepressants might help to reduce pain by decreasing the number of pain signals reaching the brain.

Nortriptyline is the antidepressant that is most commonly prescribed for face pain. It might need to be taken for several months before it becomes fully effective and for a year for people to experience lasting benefit. As with many drugs for pain, it can help some people but not others.

People taking nortriptyline rarely experience any serious side effects. People might experience mild drowsiness, a dry mouth or constipation. Nortriptyline is not suitable for everyone.

Pain management

Having strategies for coping with pain flare ups is crucial to reduce fear and the risk of depression. Because the pain is invisible, the public rarely appreciate its intensity or the significant impact it has on people's lives.

Persistent pain can affect people in many different ways. People might find that they struggle with being at work or have to stop working, their social lives can reduce and they stop enjoying their usual activities. It is common for people to worry about what is happening in their face and body and to be concerned that the pain is caused by damage. Some people might change the way they approach activities such as eating, moving their face or jaw and sometimes their upper body. This can lead to reduced fitness, weak muscles and stiff joints which can make activity even harder and everyday tasks increasingly difficult. People often say that they feel angry, frustrated, low in mood and lacking in confidence as a result of their pain. These effects can make pain harder to live with. People can find themselves trapped in unhelpful cycles that can be hard to break and leave them feeling stuck.

Pain management is a self-management approach. It involves the person with pain learning new skills to help them reduce the effect (or impact) that the pain has on them and their life. A self-management approach can be useful alongside ongoing medical treatment or if medical treatment has been stopped because it does not reduce or get rid of the pain. At this point, the self-management approach can be a very helpful alternative way of managing persistent face pain.

Clinical psychologists and physiotherapists help people to develop pain management skills. Pain management sessions can be one-to-one or in a group. The sessions will not help to cure your pain but they can help many people in different ways. For example, they can help people to:

- understand their persistent face pain;
- carry on with their everyday activities more easily and without necessarily experiencing an increase in their pain;
- return to activities which they used to enjoy but have stopped because of the pain;
- learn how to manage times of increased pain;
- improve their mood and confidence about doing things even though they have pain;
- feel more confident in their ability to manage their pain;
- work towards short-term and long-term goals such as eating crunchy food, going out for meals and returning to work or college.

Self-management of pain can result in a more enjoyable and fulfilling life despite having persistent face pain. These services might not be available in your area but if you talk to your GP they might be able to refer you to a service elsewhere.

The **British Pain Society** has produced some useful publications for patients about pain management (see [Further reading and Useful contacts sections](#)).

Useful contacts

Brain & Spine Helpline

Brain & Spine Foundation
LG01 Lincoln House
Kennington Park
1-3 Brixton Road
London
SW9 6DE

Helpline: 0808 808 1000

helpline@brainandspine.org.uk

www.brainandspine.org.uk

Run by neuroscience nurses, providing support and information on all aspects of neurological conditions for patients, their families and carers and health professionals.

Trigeminal Neuralgia Association UK

PO Box 234
Oxted
Surrey
RH8 8BE

Helpline: 01883 370214

Tel: 01883 371595

help@tna.org.uk

www.tna.org.uk

A registered charity providing support and information on trigeminal neuralgia and face pain.

Shingles Support Society

41 North Road

London

N7 9DP

Helpline: 0845 123 2305

www.herpes.org.uk/shingles-support-society

A sub-group of the Herpes Viruses Association (HVA), offering support and information on shingles and post-herpetic neuralgia.

OUCH UK (Organisation for the Understanding of Cluster Headache)

PO Box 62

Tenby

SA70 9AG

Helpline: 01646 651 979

helpline@ouchuk.org

www.ouchuk.org

Support and information on cluster headache.

Pain Concern

62-66 Newcraighall Road

Edinburgh

EH15 3HS

Helpline: 0300 123 0789

info@painconcern.org.uk

www.painconcern.org.uk

Provide information, offer support and raise awareness for those living with pain.

British Pain Society

Third Floor

Churchill House

35 Red Lion Square

London

WC1R 4SG

Tel: 020 7269 7840

info@britishpainsociety.org

www.britishpainsociety.org/people-with-pain/

A membership organisation for health professionals who care for people with pain. The website provides information for people living with pain.

Action on Pain

15 Blackthorn Drive

Scarning

Norfolk

NR19 2UJ

Helpline: 0345 603 1593

aopisat@btinternet.com

www.action-on-pain.co.uk

Run entirely by volunteers who have been affected by persistent pain, the charity provides information, offers support and campaigns for those living with pain.

NHS Choices

www.nhs.uk

NHS non-emergency number: 111

Medical advice and information on health services.

Support groups

The Brain & Spine Foundation's online discussion forum offers the opportunity to post messages, exchange views, share experiences and ask questions:

www.brainandspine.org.uk/applications/discussion

Trigeminal Neuralgia Association UK also has an online forum:

www.tna.org.uk/forum_public

Further reading

The Pain Toolkit is a website with support and information on pain self-management:

www.pain toolkit.org

Understanding & Managing Long-term Pain (2015) is a booklet produced by the **British Pain Society** to help patients living with pain. It explains what pain is, what can be done about it and who can help:

www.britishpainsociety.org/british-pain-society-publications/

The **National Institute for Health and Care Excellence (NICE)** has produced information for patients explaining the advice that they give to the NHS on caring for people with neuropathic pain:

www.nice.org.uk/guidance/cg173

Breathworks and **Headspace** are two organisations offering courses on mindfulness techniques that some people may find helpful for managing their pain:

www.breathworks-mindfulness.org.uk

www.headspace.com

The Ottawa Personal Decision Guide is a resource developed by the University of Ottawa to help people make health-related decisions:

<http://decisionaid.ohri.ca/decguide.html>

References

Details of medical references used for this booklet are available at www.brainandspine.org.uk/references or on request from the Brain & Spine Helpline: 0808 808 1000.

Thank you

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Brain & Spine Foundation

Our mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. We rely on donations to provide our services to anyone who needs us.

How to donate

- Online: www.brainandspine.org.uk/donate
- By phone: 020 7793 5900
- By post: send a cheque to the address below

Contact us

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