

Face pain



Brain & Spine
Foundation

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A guide for patients and carers

The Brain and 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.

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Introduction

This booklet provides information on face pain in adults. It focuses on chronic (long-term) face pain. The booklet describes different types of chronic face pain and provides information on common symptoms, test 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 chronic pain?

Chronic pain is long-term pain that has lasted more than three months. People can feel chronic pain anywhere in their body including the mouth or face. Very often there are no visible problems or causes.

What is chronic face pain?

People with chronic face pain experience pain because of changes to the way the nerves in the face transmit pain signals. The nerves can become extremely sensitive and pain signals 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 pain is transmitted to the brain and can be affected by a variety of factors including mood, thoughts, and activities.

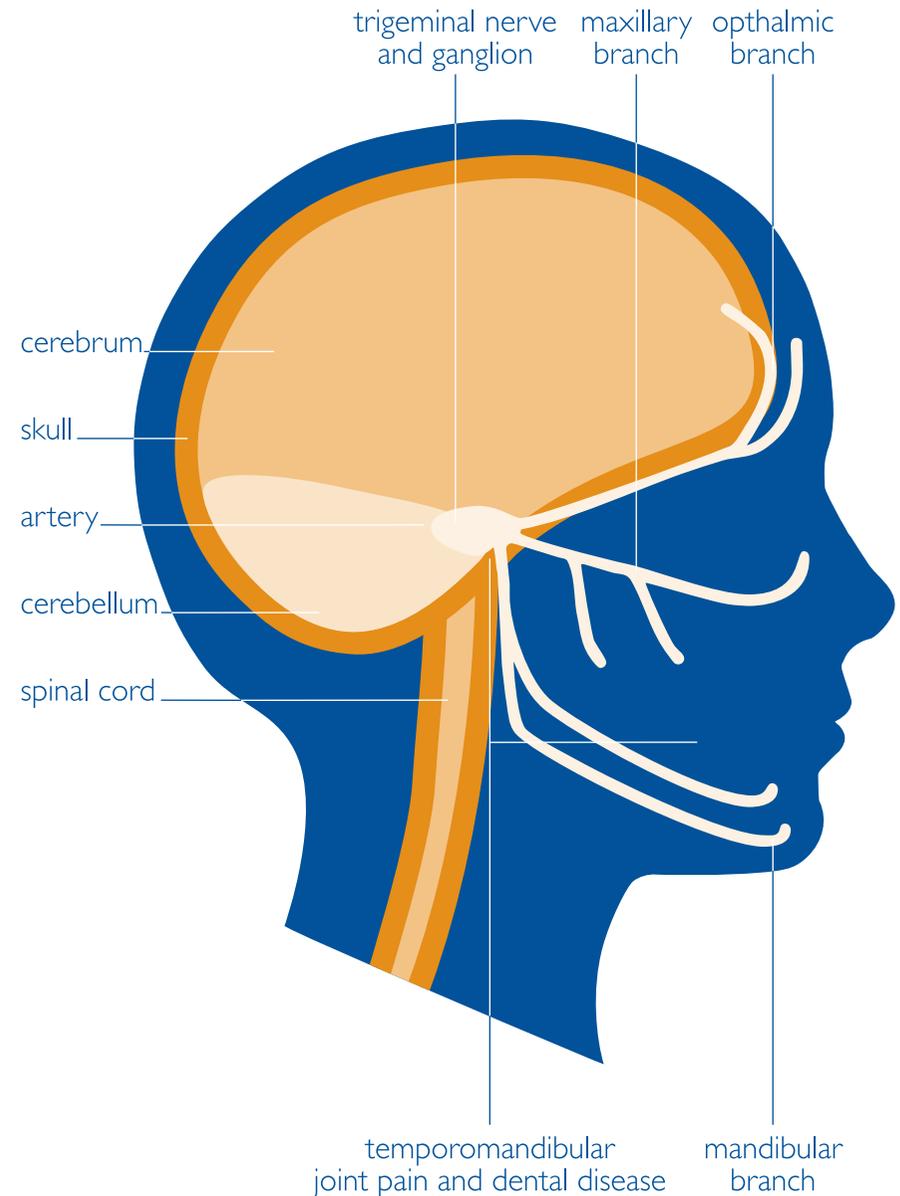
How can chronic face pain affect everyday life?

Chronic face pain can affect 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 chronic face pain is affected differently but common problems include:

- Stopping enjoyable activities
- Disturbed sleep patterns
- Feeling unhappy
- Finding it hard to speak, take part in conversations and socialise
- Worrying about the future
- Losing self-confidence
- Feeling more worried, angry or low in mood than before

Nerves and structures in the head that are involved in face pain



Trigeminal neuralgia

What is trigeminal neuralgia?

People with trigeminal neuralgia experience sudden attacks of pain on one side of their face. The pain comes and goes intermittently. Trigeminal neuralgia affects the right side of the face more commonly than the left. It very rarely affects both sides of the face.

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

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 face and one on the right side. Each nerve has three branches (hence 'tri-'). The first branch supplies feeling and sensation to the forehead, (ophthalmic branch) the second supplies the cheek (maxillary branch), and the third supplies the jaw (mandibular branch). Doctors sometimes call these branches 'divisions'.

The trigeminal nerves provide information about temperature, touch and pain from the whole front half of the head to the brain. They also control the muscles involved in chewing and equalising pressure in the ears.

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 estimated from a study of GP practices that trigeminal neuralgia affects around 0.1 per cent of the population in the UK.

What causes trigeminal neuralgia?

We do not know the exact cause for the majority of cases of trigeminal neuralgia. Different theories suggest that the underlying problem might lie within the brain, in the nerves inside the head, or in the nerve as it passes through the face.

Currently, the most popular theory is that people have a blood vessel pressing on the trigeminal nerve as it enters the brain in an area called the root entry zone. This is known as vascular compression. The pressure from the blood vessel damages the protective outer coating of the nerve (the myelin sheath). This results in the brain receiving signals from the nerve fibres that transmit pain.

Very rarely, trigeminal neuralgia can be caused by a tumour (usually benign) or a cyst pressing on the nerve.

People with multiple sclerosis can experience trigeminal neuralgia but it is extremely rare for this to be their first symptom. If you have trigeminal neuralgia, there is no reason to think you might be developing multiple sclerosis or any other serious condition.

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, lacerating, electric shock-like and shooting to describe the pain. Attacks can range from fairly mild to excruciating.

Each burst of pain lasts only a few seconds or minutes but some people might experience several bursts in quick succession and this can last for hours. Other people might experience more than 20 shorter attacks a day. For some, the pain can persist at a lower level and feel like burning or aching for some time after the main attack of sharp pain.

Trigeminal neuralgia

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 if touched. Various light touch activities can bring on the pain. For example, cleaning teeth, washing



the face, shaving, eating, talking, laughing or smiling, the wind, a light breeze or air conditioning. Attacks of pain can also occur without any trigger. This is called spontaneous pain.

People might experience pain every day for weeks or months before it disappears completely for months or even years. As time passes, the attacks can become more frequent, last longer and be more intense. Currently, there is no way of predicting when the pain will come and go. As a result, between attacks, many people are very worried about when the pain might return.

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 individuals. Many people visit their dentist when they first experience symptoms because the pain appears to come from a tooth or teeth. They might have extensive dental treatment before the diagnosis of trigeminal neuralgia is eventually made.

Because people's nerves are working normally (even though they are sensitive) 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 character of the pain: its frequency, the length of attacks, severity, location, factors that affect it, and any other features you notice.

It is important to rule out other possible causes of face and mouth pain. These include problems with the teeth, mouth, ears, skull and the glands around the mouth and the face, so these areas will be examined thoroughly. There are also a number of other conditions collectively known as trigeminal autonomic cephalalgias which produce similar symptoms. During an attack, people with these conditions also experience physical symptoms on one side of their face such as redness of the eye and face, a runny nose and often tears. (You might be interested in reading our booklet on headaches for further information.)

After being assessed, you might have a brain scan to rule out the possibility that a tumour or lesion is putting pressure on the nerves. An MRI scan might show blood vessels touching or compressing the nerve. This is thought to be the cause of the majority of cases of trigeminal neuralgia. (You might be interested in reading our fact sheet on brain scans for further information.)

Possible treatments

Medication

Anticonvulsants (or anti-epilepsy drugs) are the most common group of drugs used to treat trigeminal neuralgia. These drugs are also used to treat epilepsy. They work by reducing the activity of the nerves. Unfortunately, they do not cure trigeminal neuralgia but they can reduce the level of pain people experience. Anticonvulsant drugs need to be started at a low dose and very slowly increased to build up to the optimum dose for pain control. The possible side effects of anticonvulsants include drowsiness, fatigue (severe tiredness) and difficulties concentrating. In higher doses, the possible side effects include balance problems, memory problems and double vision.



Carbamazepine (brand name Tegretol) is the drug of first choice in the UK. It is effective for many people but, unfortunately, the possible side effects are often quite severe, especially in higher doses. It can also cause a rash in around 7 per cent of people who take it. (This is particularly likely to happen in Han Chinese and Thai people.) If this occurs, you should seek advice from your doctor and stop taking the drug. Carbamazepine can interfere with the action of many other drugs 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, 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. However, for 75 per cent of people with trigeminal neuralgia, carbamazepine is an effective treatment.

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. It is used in a similar way to carbamazepine. You will need to have regular blood tests with this drug, especially if you are taking a higher dose.

Phenytoin (brand name Epanutin), sodium valporate (brand name Epilim) and clonazepam (brand name Rivotril) are anticonvulsant drugs that are prescribed instead of carbamazepine, or possibly with carbamazepine. They might not 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 particular drugs are effective in treating trigeminal neuralgia.

Baclofen is a muscle-relaxing drug often used for people with multiple sclerosis. For people with trigeminal neuralgia, it is usually combined with carbamazepine or phenytoin and can be effective in the early stages of the condition.

Lamotrigine can be effective for people with trigeminal neuralgia when it is prescribed with carbamazepine. It needs to be started at a very low dose and gradually increased to control side effects such as a rash.

The dosage of all these drugs can be increased over time if the pain becomes more severe. If your face pain disappears for over a month, the drugs should be slowly withdrawn and only restarted if the pain returns. Many people find it helpful to keep a record of changes in the severity of their pain 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 1 to 10 scale), how the pain has affected your everyday activities (on a 1 to 10 scale), the drugs you are taking, and any side effects you are experiencing.

Possible treatments

Surgery

Drugs, initially, are the best form of treatment for trigeminal neuralgia if they are controlling the pain. However, if drugs fail to relieve the pain or cause unmanageable side effects, you might need to consider surgery. It is important that you discuss the options with a neurosurgeon in the early stages of trigeminal neuralgia and that you have all your questions about surgery answered. Evidence is beginning to emerge that surgery carried out in the earlier stages of trigeminal neuralgia might result in improved outcomes. Operations to treat face pain are mainly performed by a neurosurgeon - a specialist doctor who carries out surgery on the brain and spine (neurosurgery). Some of the procedures can be carried out by pain medicine doctors. There are different types of surgery used to treat trigeminal neuralgia.

Interrupting the nerve

Different surgical methods are used to interrupt or block activity in the trigeminal nerve. These methods can relieve the pain but, unfortunately, they nearly always leave an area of numbness or loss of feeling in the face because part of the nerve is destroyed.

The nerve can be interrupted at one of three sites:

1. The outside of the face

The small branches of the trigeminal nerve that pass 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 as a minor surgical treatment. People might be left with a small area of numbness in their face. Unfortunately, the pain is often only reduced for around ten months. Interrupting the nerve on the outside of the face is usually only recommended when other treatments are not possible.

2. The ganglion

The Gasserian ganglion (or trigeminal ganglion) is just inside the bottom of the skull. It is a group of nerve cell bodies on the trigeminal nerve the size and shape of a split broad bean. It contains the cells that supply the nerve fibres of the trigeminal nerve and is the point at which all the branches of the nerve meet.

To reach the ganglion, the surgeon passes 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 then deactivates the ganglion by injecting it with glycerol or applying heat to it (thermocoagulation). Alternatively, the surgeon or specialist might compress the nerve with a tiny inflatable balloon positioned at the tip of the needle (balloon microcompression).

The procedures to interrupt the trigeminal nerve at the ganglion are usually carried out with the person under heavy sedation and partially awake so the surgeon can confirm that the needle has reached the correct place by checking their responses to stimulation. An overnight stay in hospital might be required for these procedures.

Interrupting the nerve at the ganglion usually allows the surgeon to treat larger areas of the face. Unfortunately, the majority of people having this surgery will be left with an area of numbness in their face. The numbness is usually less severe than the numbness following a neurectomy. People often describe the feeling as similar to a dental injection wearing off. Around 2 per cent of people will experience a condition called anaesthesia dolorosa after the surgery. Anaesthesia dolorosa is severe, dull, continuous pain in the numb area of the face. There is currently no cure for this condition. Around 10 per cent of people will experience some long-lasting or even permanent unpleasant sensations in their face after the surgery. The unpleasant sensations might be severe enough to affect the quality of people's lives.

Possible treatments

There are other possible risks with the techniques used to interrupt the nerve at the ganglion and people should consider them carefully before deciding to go ahead with the surgery. As the needle passes into the skull, there might be complications that affect the brain. Less than 1 per cent of people are at risk of complications such as meningitis, brain abscesses, brain haemorrhages or heart attacks following the surgery. These are serious complications and can result in permanent mental and physical disabilities or death.

It is sometimes difficult for the surgeon to position the needle into the part of the nerve supplying 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. An unfortunate result is that around 8 per cent of people in this situation experience a loss or reduction in their eye (corneal) reflex. This means that they cannot feel anything touching the eye so there is a risk of further problems if the eye becomes scratched or infected.

Around 10 per cent of people experience some difficulties with eating for a few months after the surgery, mainly after balloon microcompression.

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.

3. The nerve trunk

The nerve trunk is the portion of the trigeminal nerve that emerges from the brain and extends to the ganglion. The procedure to interrupt the nerve at this point is called a partial sensory rhizotomy. It is less common than it used to be and is now carried out on relatively few people.

Under a general anaesthetic, an opening is made at the base of the skull just behind the ear. The surgeon identifies the trigeminal nerve using a microscope and cuts or crushes it to divide the nerve fibres supplying feeling to the parts of the face affected by pain. You will need a hospital stay of three to five days and around six weeks off work. People sometimes experience areas of numbness after this procedure.

Interrupting the nerve at the nerve trunk often provides a long-term cure for trigeminal neuralgia. The main disadvantage is the risk associated with surgery on such an important part of the brain. Even with the expert hands of a neurosurgeon taking the greatest possible care, the risks of this procedure are greater than the risks of alternative procedures. The exact risk differs for individuals depending on factors such as age and general health but overall there is a 0.5 per cent risk of death and a 1 per cent risk of serious physical disability.

There is also a risk that the nearby nerves coming from the brain stem will be damaged during the procedure. These include the nerves supplying hearing and balance and 4 per cent of people experience balance problems and deafness in one ear after the surgery. More rarely, people can experience weakness in the face (on the side of the operation), difficulties with swallowing, or double vision. Just less than 2 per cent of people experience damage to nearby nerves during the procedure. Some find that resulting problems can improve over the months following the surgery.

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 also a risk of anaesthesia dolorosa after the procedure.



Possible treatments

Stereotactic radiosurgery (gamma knife)

Stereotactic radiosurgery (also known as gamma knife) is a newer treatment for trigeminal neuralgia. It is only available in a few specialised neurological centres in the UK. It involves interrupting the trigeminal nerve with high energy beams of radiation focused just behind the ganglion. It is not a surgical procedure and no incision (cut) is made. It is carried out with MRI scanner equipment. You will be fitted for a special metal frame to keep your head still. The treatment can take a few hours. You might need to stay overnight in hospital.

Early results of stereotactic radiosurgery suggest that people experience similar rates of pain relief to those achieved by other procedures that interrupt the nerve at the ganglion. The results for long-term pain relief are the same as those for other procedures. However, a disadvantage of stereotactic radiosurgery is that pain relief can be delayed for a few months and people might experience areas of numbness up to six months after the treatment. A very small minority of people might develop anaesthesia dolorosa.

Microvascular decompression of the nerve (MVD)

The surgical procedure of microvascular decompression (or neurovascular decompression) has been developed to provide treatment for trigeminal neuralgia without the risk of nerve damage, numbness or anaesthesia dolorosa.

With this treatment the surgeon makes an opening at the base of skull behind the ear (the same approach as a rhizotomy). The blood vessel pressing on the trigeminal nerve as it emerges from the brain stem is gently moved away and a variety of methods are then used to make sure the nerve is not compressed by a blood vessel. This is often done with fine strips of Teflon. 90-95 per cent of people

experience immediate pain relief with this procedure and there is evidence to show that around 70 per cent of people are free of face pain ten years afterwards. Decompression of the nerve rarely results in areas of numbness or loss of feeling. There have been no reported cases of anaesthesia dolorosa.

The main disadvantage of this procedure is that it involves surgery on an important part of the brain and carries the same risks of serious complications as interrupting the nerve at the nerve trunk (rhizotomy). You will need to stay in hospital for three to five days. Most people recover fully within six weeks. The most common immediate complication is cerebrospinal fluid (the fluid surrounding the brain and spinal cord) leaking from the nose. This might require a further short operation. The other complications are the same as those for the partial sensory rhizotomy but the risk of numbness is extremely small.

Neurostimulation

As with several chronic pain conditions, attempts have been made to treat trigeminal neuralgia and other forms of 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 minority of people with chronic face pain for whom it might provide some benefits. To receive neurostimulation, you will need to be referred to an expert in this treatment. You can discuss your options with your doctors. Currently, there is no evidence for its effectiveness in treating facial pain.

Possible treatments

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 as an individual. However, if the pain is not controlled by drugs or you experience unmanageable side effects, you might need to give careful consideration to the surgical treatment options available. You should discuss the options with your medical and surgical team and be involved in any decisions about your treatment. Further support and information is available from patient support groups (see the Useful Contacts section).

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, the general view among specialists is that for healthy people microvascular decompression (decompression of the nerve) is likely to be the best option. 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 are unwilling 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 also be repeated. Stereotactic radiosurgery (gamma knife) 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 might be 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 nature of the pain is identical and affects one side of the face. 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 chronic face pain after an attack of shingles on the face. The type of pain that occurs with post-herpetic neuralgia is called neuropathic pain.

People with post-herpetic neuralgia usually experience a burning, aching or throbbing pain that is often accompanied by extreme tenderness. People 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 is reduced.

What is shingles?

The medical name for shingles is herpes zoster. Shingles is caused by the chicken pox 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, suddenly attacks one nerve 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 affects one side of the face.

Shingles can begin with a dull pain in the skin on the face. 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 and antidepressants. 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 chicken pox virus damages the nerve and the area of skin supplied by that nerve goes partly numb. People experience pain in this area. The pain happens because the nerve continues to send pain signals to the brain.

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. Around 100,000 people develop post-herpetic neuralgia on some part of their body each year in the UK. Only a small number of them 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 should 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.

Other types of face pain



The main drugs used to treat post-herpetic neuralgia are amitriptyline or nortriptyline. These drugs are more commonly used to treat depression but they can have a very powerful effect on certain forms of nerve pain. For some people, they can reduce the pain by 30 per cent. It might take two to three weeks before they begin to provide any pain reduction. People might need to take these drugs for several months.

Other medicines prescribed to treat post-herpetic neuralgia include creams and lotions. These act as local anaesthetics and numb the area. There are also patches that contain an anaesthetic (for example, lidocaine). The patches look like regular plasters.

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

The National Institute for Health and Clinical Excellence (NICE) have issued guidelines on the treatment of neuropathic pain conditions such as post-herpetic neuralgia (see the Further Reading section).

Temporomandibular disorders (TMDs)

Temporomandibular disorders (TMDs) are known by several different names including facial arthromyalgia. The temporomandibular joint (TMJ) 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. 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:

- 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.)
- Pain, discomfort and tenderness in the jaw joints and surrounding muscles
- Dull, aching pain (but sometimes the pain is sudden and sharp)
- Locking of the jaw when you open your mouth
- Reduced opening of your mouth

Other symptoms include:

- Earache, buzzing in the ear, or a feeling of 'fullness' in the ear
- Headache and migraine
- Aching in the neck
- 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, clenching or grinding the teeth, 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 rare 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.

Other types of face pain

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. Because splints are devices that cover some or all of the teeth they 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, it can be helpful to:

- 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, try not to avoid opening your mouth widely.
- 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).



Other conditions that can cause chronic face pain

There are other conditions that can cause chronic face pain. These are discussed below. Some of these conditions have more than one name. Whichever names are used for the conditions there is still considerable speculation on what causes them. Essentially, the management of the conditions is the same.

Chronic idiopathic facial pain (previously known as 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 the usual pain relief medications. Chronic idiopathic facial pain can be intermittent or continuous, vary in intensity, and 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.

Other types of face pain

Chronic 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 chronic idiopathic facial pain so doctors rely on people offering accurate and specific descriptions of their symptoms.

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

Odontalgia is the medical word for toothache. 'Atypical' refers to the pain not being caused by dental problems. 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. Dental treatment or tooth removal will not stop the pain. As with many types of face pain, it is the pain signal mechanism that has become faulty.

Burning mouth syndrome

Burning mouth syndrome (BMS) is the name for a group of conditions that cause 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 patients 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). Blood tests might be carried out to check for conditions such as diabetes, anaemia and vitamin deficiencies.

What are the treatments for chronic 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 (also called 'pain management').

Medication

Pain relief drugs such as paracetamol, aspirin or ibuprofen do not usually help people with chronic face pain. People are often prescribed antidepressant or anticonvulsant (anti-epilepsy) 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. Those who do find it helpful might experience up to a 50 per cent reduction in their pain.

People taking nortriptyline rarely experience any serious side effects. People might experience mild drowsiness, a dry mouth or constipation. Drowsiness and constipation tend to be worse for elderly people. People with certain conditions such as glaucoma or prostate problems should not take nortriptyline.

Pain management



Chronic 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 it is causing damage. This might lead them to 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 lack confidence as a result of their pain. These effects can make pain harder to live with. People can find themselves trapped in unhelpful cycles which can be hard to break and leave them feeling stuck.

Pain management is a self-management approach that 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. Sometimes a self-management approach can be useful alongside ongoing medical treatment. However, for some people, medical treatment might have been stopped because it will not reduce or get rid of the pain. At this point the self-management approach can be a very helpful alternative way of managing chronic face pain.

Pain management

Clinical psychologists and sometimes 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 chronic 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, returning to work or college

Self-management of pain can result in a more enjoyable and fulfilling life despite having chronic 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.

Useful contacts

Face pain:

Brain and Spine Helpline

Brain and Spine Foundation
3.36 Canterbury Court
Kennington Park
1-3 Brixton Road
London SW9 6DE

0808 808 1000

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:

Trigeminal Neuralgia Association

PO Box 234
Oxted
Surrey RH8 8BE

01883 370214

www.tna.org.uk

Support and information on trigeminal neuralgia and face pain.

Useful contacts

Pain:

British Pain Society

Third Floor
Churchill House
35 Red Lion Square
London WC1R 4SG

020 7269 7840

www.britishpainsociety.org

Cluster headache:

OUCH UK (Organisation for the Understanding of Cluster Headache)

PO Box 62
Tenby SA70 9AG

01646 651 979

www.ouchuk.org

Support and information on cluster headache.

General health:

NHS Choices

www.nhs.uk

NHS Direct

0845 46 47

Medical advice and information on health services.

Support groups

The Brain and 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

'Manage Your Pain: Practical and Positive Ways of Adapting to Chronic Pain' by Michael Nicholas, Allan Molloy, Lois Tonkin and Lee Beston (Souvenir Press, 2003). ISBN 978 0 285 64048 1.

'Overcoming Chronic Pain: A Self-help Guide Using Cognitive Behavioral Techniques' by Frances Cole, Helen Macdonald, Catherina Carus and Hazel Howden-Leach (Robinson, 2005). ISBN 978 1 841 199702.

www.paintoolkit.org is a website with support and information on pain self-management.

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>

Neuropathic pain: pharmacological management (NICE Clinical Guidelines CG96, March 2010). www.nice.org.uk

<http://publications.nice.org.uk/neuropathic-pain-cg96>

References

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

Thank you

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Brain and Spine Foundation



The Foundation provides support and information to those affected by the many conditions associated with the brain and spine. The charity relies heavily on voluntary donations and fundraising events to provide the services which have helped many thousands of people across the UK.

You can help the future work of the Brain and Spine Foundation by

- Making a donation
- Organising or taking part in a fundraising event
- Offering your time as a volunteer
- Remembering the Brain and Spine Foundation in your will

Further details available from the address/telephone number below or from www.brainandspine.org.uk.

Brain and Spine Foundation

3.36 Canterbury Court, Kennington Park, 1-3 Brixton Road
London SW9 6DE

Telephone (switchboard): 020 7793 5900

Helpline: 0808 808 1000

www.brainandspine.org.uk

Registered Charity Number: 1098528

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