

Cluster Headaches

Cluster headaches occur as attacks of severe, one-sided headaches. Typically, a number of attacks occur over several weeks - a bout (cluster) of attacks. The headaches then usually go for weeks, months or years until a next cluster of headaches develops.

An injection with a migraine medicine called sumatriptan, or a nasal spray containing a medicine called zolmitriptan, or breathing 100% oxygen, will usually relieve each headache. Some medicines are also used to prevent the headaches. Avoidance of alcohol is recommended during a period of cluster headaches.

What are cluster headaches and what are the symptoms?

Cluster headaches consist of attacks of severe one-sided pain in the head. It is sometimes called migrainous neuralgia. Each attack develops suddenly, usually without any warning. Typically, you feel the pain mainly in or around one eye or temple. The pain may spread to other areas on the same side of the head. The pain is sometimes described as burning or boring. One attack lasts 15-180 minutes, but most commonly 45-90 minutes. Attacks may occur from once every two days to eight times a day.

The pain during an attack is usually severe. It can be so severe that you become agitated and unable to lie down. Some people even bang their head against the wall in frustration with the pain. Attacks often occur at night, a couple of hours after falling asleep, and will wake you from sleep.

During each attack you may also experience other symptoms. These include:

- Redness and watering of the eye.
- A runny and bunged-up nose.
- Sweating of the face.
- Swelling of the eyelids.
- Drooping of the eyelid.
- Constriction of the pupil in the eye.

Attacks usually occur in bouts (clusters). That is, a number of attacks of pain occur over a period of time, which then stop. During a cluster, each attack of pain usually occurs on the same side of the head. Each cluster of attacks usually lasts for several weeks or months. Each cluster is then usually separated by months or years of remission (where no attacks occur). However, the frequency of clusters can vary greatly from person to person. For example:

- A fairly typical case is for a cluster to last 6-12 weeks once a year, or once every two years, and at about the same time of year.
- Some people have more frequent clusters, some fewer, than the above.
- In a small number of cases only one cluster of attacks ever occurs.
- In about 1 in 10 cases, attacks continue without any remission periods. (This is called chronic cluster headache.)

Who gets cluster headaches?

Cluster headaches affect about 1 in 1,000 people. They are four times more likely to occur in men than in women. The first bout (cluster) typically develops between the ages of 20-40 years, but it can start at any age.

What causes cluster headaches?

Research suggests that a part of the brain called the hypothalamus becomes overactive during each attack, although it is not known what causes this to happen. During an attack, the hypothalamus is thought to release chemicals (neurotransmitters). These may stimulate nerve cells in the brain to cause the pain and other symptoms. The nerve overactivity may also cause a widening or opening up (vasodilation) of the blood vessels in the affected side of the brain. One theory is that the pain is caused by the widening of these blood vessels which then press on nearby tissues in the brain, which can cause pain. However, this is just a theory and the exact cause of the pain is not known.

The hypothalamus is a part of the brain thought to be concerned with the body clock (circadian rhythms). This may be linked to the fact that many people with cluster headaches have their bouts (clusters) at the same time each year, and each headache attack often occurs at about the same time each day.

Most cluster headaches occur for no apparent reason. However, some people find that something may trigger a headache. If you find that something triggers a headache, it is best to avoid it for the duration of a cluster period (until you are in remission). For example:

- Alcohol. Some people find that a headache often occurs within an hour or so of having an alcoholic drink. It is usually advised to stop drinking alcohol completely for the duration of a cluster period.
- Being hot may be a trigger, such as exercising in a hot room, or having a hot bath.
- Strong-smelling substances, such as solvents, perfumes, petrol, etc.

Almost all people with cluster headaches have no abnormality of the brain that can be shown by scans or tests. In about 1 in 20 people there is another family member who also suffers from cluster headaches. In a very small minority of cases, cluster headaches seem to be triggered by a tumour in the pituitary gland (pituitary adenoma) or other brain tumours. (The pituitary is a small gland at the base of the brain.) It has to be stressed that this is a rare cause of cluster headaches.

How are cluster headaches diagnosed?

The diagnosis is based on the typical symptoms. There is no test that can prove the diagnosis. Tests are sometimes done if the diagnosis is not clear, to rule out other causes of headache. Sometimes tests such as a brain scan may be done to rule out a pituitary adenoma (as described above). Your GP may therefore refer you to a doctor with a special interest in the treatment of headaches.

What is the treatment for cluster headaches?

Treatment is divided into treatments to stop (relieve) each headache, and treatments aimed at preventing the headaches.

Treating each headache

Ordinary painkillers do not work. Generally, if you take an ordinary painkiller, it takes too long to work, as the headache will usually have gone before the painkiller takes effect.

Sumatriptan injection: [sumatriptan](#), given by injection just under the skin, is the commonly used treatment to abort a headache. It relieves pain within 15 minutes in about three in four people with a cluster headache. You can be shown how to use this injection, and should use it as soon as a headache occurs.

Sumatriptan is a class of medicine called a triptan, more usually used to treat migraine. It is not a painkiller. Triptans work by interfering with a brain chemical called 5HT. This chemical is thought to be involved in both migraine and cluster headaches.

Useful facts about sumatriptan injection:

- It works within 5-15 minutes to ease the headache in most affected people.
- The adult dose is a 6 mg injection for each headache. The maximum dose in 24 hours is two 6 mg injections (12 mg) with a minimum gap of one hour between the two doses.

- Side-effects sometimes occur but, if they do, are generally mild and do not last long. They include feeling sick (nausea), dizziness, tiredness and dry mouth. A minority of people also develop a warm-hot sensation, tightness, tingling, flushing, and feelings of heaviness or pressure in the face, arms, legs, and occasionally the chest.
- Some people should not take sumatriptan - for example, some people with heart disease, stroke disease or peripheral vascular disease.

Zolmitriptan nasal spray: **zolmitriptan** is also a triptan medicine. Zolmitriptan nasal spray is an alternative to sumatriptan injection. It often works well but possibly not as quickly as sumatriptan injection.

100% oxygen therapy: this is an alternative treatment that may be advised, especially if sumatriptan injections or zolmitriptan nasal spray cannot be used, or do not work. It often works well to relieve pain within 15 minutes, but it does not work in everybody. Its advantage, when it works, is that it can be used as often as necessary. The oxygen has to be 100% and so needs to be delivered, through a special mask, from an oxygen cylinder. Some people with cluster headaches have an oxygen cylinder and mask at home ready to treat an attack.

100% oxygen treatment may not be suitable for people who also have chronic obstructive pulmonary disease (COPD).

Other treatments: sumatriptan injections, zolmitriptan nasal spray or oxygen are usually the first-line treatments. Other treatments that are sometimes used include sumatriptan nasal spray and ergotamine injection. In general, these are often not as good as the first-line treatments.

It is sometimes difficult for doctors to rule out another type of headache called paroxysmal hemicrania. This is a rare condition of unknown cause which causes one-sided headaches similar to cluster headaches. Sometimes a doctor will prescribe a one-week trial of an anti-inflammatory painkilling medicine called **indometacin**. This will almost always take away the pain of paroxysmal hemicrania, but will have no effect on cluster headaches.

Preventing cluster headaches

Some medicines are used in an attempt to prevent cluster headaches. Most people with cluster headaches will be prescribed one. It is difficult to say exactly how well they work at reducing the frequency and/or severity of headaches. This is because there is a lack of large research trials which have studied these treatments. However, smaller research studies suggest that they do work for many people. The usual treatments to be used in this way are

- **Verapamil.** This is the most commonly used treatment. It is a medicine that is normally used to treat heart problems. It is not clear how it works for cluster headaches. The doses used are often higher than those used for heart problems, and you may need heart tests such as an **electrocardiogram (ECG)** before increasing to high doses.
- **Lithium.** This medicine is more commonly used to treat bipolar disorder. It is not clear how it may help cluster headaches. It is most effective in chronic cluster headache. You need regular blood checks to measure the level of lithium in the blood to make sure the dose is correct.
- Methysergide can be effective in short-term bouts of cluster headache but cannot be used for more than six months at a time due to potential side-effects.
- **Corticosteroids** are used in a short burst for two to three weeks in decreasing amounts as a first step to break the headache cycle. They are often used alongside other treatments which take longer to work. Corticosteroids are more effective for chronic cluster headache to break the cycle. If used for episodic cluster headache, when the medication is reduced the headaches come back.
- Ergotamine is sometimes prescribed. It can be helpful in reducing attacks at night if you take it at bedtime.
- **Topiramate** has been reported to be useful in cluster headache.
- Research continues to find better treatments for this very painful condition.
- There have been anecdotal suggestions that alternative therapies such as acupuncture can be helpful in the treatment and prevention of cluster headache but as yet there is no good quality supporting evidence for this. Further research may be helpful in this area.

Some notes about preventative medicines for cluster headaches

- Preventative treatment is often taken intermittently - that is, just for the duration of a cluster period. Treatment is typically continued until you are headache-free for 14 days; then you can stop to see if the cluster has ended.
- Some people take preventative medication indefinitely. It depends on how often, and for how long, your cluster periods occur. In particular, people with chronic cluster headache may take preventative medication indefinitely.
- It is often through trial and error that you find out which preventative treatment works best for you.
- Many people start with verapamil, built up as quickly as possible to the maximum tolerated dose. If this is not found to help within one week, it may be stopped and another tried.
- Treatment with a single medicine is preferred, but a combination of medicines may sometimes be necessary.
- Once an effective preventative treatment has been found for an individual, this can be restarted when the next cluster period begins.
- Preventative treatments that have previously worked well do not always continue to work for future cluster periods.
- When this occurs, an alternative preventative treatment can be tried.
- All the medicines used to prevent cluster headaches have potential side-effects and may not be suitable for everyone. However, sometimes a trade-off has to be taken. That is, accepting that some side-effects may be the price to pay for relief of the headaches.

Further help & information

OUCH (UK) - Organisation For The Understanding Of Cluster Headaches

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Further reading & references

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