

## Cluster Headache

This rare type of headache is one of the most painful conditions an individual can experience. The fact sheet aims to give you key information on cluster headache, its management and treatment. It is one of a series written and researched by The Migraine Trust to help you understand and manage your condition.

Cluster headache affects about 1 to 2 people in every 1,000. The pain of a cluster headache is described as excruciating and even more debilitating than migraine.

### What are the symptoms?

The symptoms of cluster headache are very typical. The pain in your head is always unilateral (one sided), although for some people the side can vary from time to time. The pain is usually centred over one eye, one temple or the forehead. It can spread to a larger area making diagnosis harder.

During a bout of cluster headache the pain is often experienced at a similar time each day. The headache often starts at night waking people one to two hours after they have gone to sleep. The pain usually reaches its full intensity within 5 to 10 minutes and lasts at this agonising level for between 30 and 60 minutes. For some people the pain can last for 15 minutes, for others 3 hours has been known. It then stops, usually fairly abruptly.

You may experience the head pain every other day during a bout, or up to 8 times per day during a bad cluster.

In about 80% of people with cluster headache the bouts (or "clusters") of head pain last for 4 to 12 weeks once a year often at the same time and often in the Spring or Autumn. It may then disappear for several months or even years. This is known as episodic cluster headache. The reason for this seasonal timing is not completely known, although it

is one of the key aspects of diagnosis and may involve a brain area called the hypothalamus. The remaining 20% of people do not have these pain free intervals and are said to have "chronic cluster headache."

People with cluster headache are usually unable to keep still during an attack and often try to relieve the agonising pain by pacing the room or walking outside, sometimes even banging their heads against a wall until the pain subsides.

Other symptoms which are characteristic of cluster headache are a blocked or runny nose, and on the same side of the head as the pain, a drooping eyelid and watering and redness of one eye. Many people also experience a flushed or sweating face.

### Who can get cluster headache?

Cluster headache can start at any age but most commonly starts in your 20's or older. You are not likely to grow out of cluster headache, although as you get older it is likely that the pain free periods between bouts of cluster headache will get longer.

Approximately 1 in 20 people with cluster headache have a family member who also has the condition. Unlike migraine, it is more common in men than women (by five to six times). It is also more common in heavy smokers.

As with all forms of headache, cluster headache occurs in children but it is less common than in adults.

### **Obtaining a diagnosis**

There is no special test to diagnose cluster headache and so your doctor will need to take a very detailed history of all your symptoms in order to make the correct diagnosis. You may be referred for an MRI scan to rule out other causes for the pain starting suddenly.

You are likely to be referred to a headache specialist in a hospital or headache clinic. This is because this is a rare condition which GP or family doctors do not often treat, not because it is dangerous or life threatening.

### **What triggers cluster headache?**

Alcohol is one well known trigger of cluster headache, often bringing on the pain within an hour of drinking. If you have cluster headache you should not drink any alcohol during a cluster period. Once the bout is over you will be to drink alcohol again.

A significant number of people find that strong smelling substances such as petrol, paint fumes, perfume, bleach or solvents can trigger an attack. During an episode of cluster headaches you should try to avoid these things.

Some people find exercise or becoming over heated will bring on an attack, so again avoiding these is the best advice during a bout.

Research has showed that heavy smokers are at an increased risk of developing chronic cluster headache so giving up smoking or cutting down is worth considering.

### **Treatment**

Whilst there is currently no cure for cluster headache, the treatment has become much more effective in the last 10 years.

**Acute treatment** is used to stop the pain once it has started. Treating cluster headache can be tricky because the pain becomes extremely severe very quickly – usually within 10 minutes. Thus the key to treating cluster headache during an attack is speed to reduce the excruciating pain as fast as possible.

Ordinary painkillers that you can buy over the counter are not usually effective, as the pain of cluster headache is too intense and they take too long to work.

- **Oxygen** is one of the safest ways to treat cluster headache. You need to breathe the oxygen in at a rate of between 7 and 12 litres per minute. The treatment usually starts to work within 15 to 20 minute. For some people the attack is delayed rather than stopped altogether.

From 1 February 2006, new regulations were introduced on the way oxygen is prescribed and delivered to people's homes. Up to this time people with cluster headache obtained their oxygen cylinders from their chemist using a doctor's prescription.

Your doctor will now need to send a **Home Oxygen Order Form (HOOF)** to one of the 4 companies who has the contract to deliver oxygen in your area (list at end of fact sheet). You will also need to complete a **Home Oxygen Consent Form (HCOF)**, enabling the supplier to receive information about you in accordance with the Data Protection Act.

If you are already using oxygen your GP can complete the HOOF form when you need a repeat prescription. If you are trying the treatment for the first time you may need to be referred to a specialist. It is worth asking the doctor to state that the oxygen is for cluster headache so that the supplier knows a high flow regulator is needed to ensure you get the oxygen at the required rate. The cylinders will then be delivered with the correct regulator, masks and any other equipment you may need. If you have queries on your supply, each contractor has a helpline (numbers at end of this fact sheet).

When the local contractor has the HOOF form you can ring them directly to re-order the cylinders. These should be delivered within 3 working days.

- **Sumatriptan injections** have been found to reduce the pain within 10 minutes during an attack. In general tablets are less effective if you have cluster headache because of the time they take to work.

- **Sumatriptan and zolmitriptan nasal sprays** do help some people although the onset of action maybe slower than the injection.

**Preventative treatment** is used to try and stop the attack from starting in the first place. There is a far wider range of preventative treatments available now than in the recent past. You will need to take the preventative treatment when the cluster period starts and continue for about two weeks after the bout has ended. You will need to stop the drugs gradually and restart them if a new bout begins.

The most common preventative treatments are:

- **Verapamil** prescribed for cluster headache as research has shown that a daily dose can be effective in both episodic and chronic cluster headache. You will probably need to see a specialist in a hospital or clinic if you are prescribed this drug, because your heart will need to be monitored regularly using an ECG machine whilst the correct dose for you is established.
- **Methysergide** is effective in episodic (short term bouts) of cluster headache but needs caution in the treatment of chronic cluster headache as **you should not take this for more than six months at a time.**
- **Lithium** at a low dose can be effective although again this will need careful monitoring. It is more

effective in treating chronic cluster headache than episodic.

- **Corticosteroids** are given because they are fast acting. They can be used in a short burst for 2 to 3 weeks in decreasing amounts as a first step to break the 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 infrequently prescribed. It can be helpful in reducing attacks at night if you take it at bedtime.
- **Topiramate** has recently been reported to be useful in cluster headache.

As with any drug treatment you may need to work with your doctor to determine what works best for you. You may need to try several treatment regimes before you discover the best one for you.

#### **Future research**

More research needs to be done on what triggers cluster headache. As advances are made in functional neuro-imaging this debilitating condition will become better understood and so treatments will also become effective.

## PROVIDERS OF OXYGEN CYLINDERS

Regions covered	Company	Helpline Number
North West, Yorkshire & Humberside, Leicestershire, Northamptonshire, Rutland, Shropshire, Staffordshire, Trent, East Midlands, West Midlands, North, NE, NW and Central London, South West Peninsula, Dorset, Somerset, Avon, Gloucestershire, Wiltshire and Wales	Air Products	0800 373580
Bedfordshire, Hertfordshire, Essex, Norfolk, Suffolk and Cambridge	British Oxygen (medical)	0800 136603
SE and SW London, Kent & Medway, Surrey, Sussex, Thames Valley, Hants & Isle of Wight	Allied Respiratory	0500 823773
County Durham and Tees Valley, Northumberland and Tyne & Wear	Linde Gas UK	0808 202 0999

**ALWAYS CONSULT YOUR DOCTOR BEFORE TAKING OR CHANGING ANY TREATMENTS. THIS INFORMATION SHOULD NOT BE A SUBSTITUTE FOR YOUR DOCTOR'S ADVICE.**

## Further useful contacts:

### **OUCH (UK) (for Cluster Headaches)**

Pyramid House  
956 High Road  
London  
N12 9RX  
24 Hour Helpline: 01646 651 979  
Website: [www.ouchuk.org](http://www.ouchuk.org)

### **Pain Concern**

PO Box 13256  
Haddington EH41 4YD  
Tel: 01620 822572

### **World Headache Alliance**

Email: [mail@w-h-a.org](mailto:mail@w-h-a.org)  
Website: [www.w-h-a.org](http://www.w-h-a.org)

**This fact sheet is available in larger print on request.**

This fact sheet was produced by the Education Department at The Migraine Trust. The information in this fact sheet has been read and checked for accuracy and relevance by headache professionals and people living with migraine. Date Reviewed March 2009

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