

Lifting The Burden

The Global Campaign against Headache

A collaboration between the World Health Organization, non-governmental organisations, academic institutions and individuals worldwide

Information for people affected by cluster headache

Headache disorders are real – they are not just in the mind.

If headache bothers you, it needs medical attention. The purpose of this leaflet is to help you understand your headache, your diagnosis and your treatment, and to work with your doctor or nurse in a way that will get best results for you.

What is cluster headache?

"They often wake me in the middle of the night, a couple of hours after I've gone to bed. They build up in a matter of seconds and the pain is just excruciating. It's only in my right eye, like a red hot poker. I don't know where to put myself. I have to do something to distract from the pain. Sometimes I pace up and down the room holding my head, or just sit in the chair and rock."

Cluster headache is the name given to short-lasting attacks of very severe one-sided head pain, usually in or around the eye. These usually start without warning, one or more times every day, generally at the same times each day or during the night. Quite often, the first one will wake the person up an hour or so after falling asleep.

Cluster headache is sometimes said to be a type of migraine, but this is not so. It is a quite distinct headache and needs different treatment from migraine.

Who gets cluster headache?

Cluster headache is not common. It affects up to three in every 1,000 people. Men are five times more likely than women to have cluster headache, which makes it unusual among headache disorders. The first attack is likely to happen between the ages of 20 and 40, but cluster headache can start at any age.

What are the different types of cluster headache?

Episodic cluster headache is more common. This type happens daily for limited periods (*episodes*) and then stops, a feature giving rise to the term "cluster". Usually these periods last from six to 12 weeks, but they can end after two weeks or go on for anything up to six months. They tend to come at about the same time each year, often spring or autumn, but some people have two or three episodes every year and others have gaps of two or more years between episodes.

In between, people with episodic cluster headache have no symptoms of the condition at all.

Chronic cluster headache, which accounts for about one in 10 cases of cluster headache, does not stop. Daily or near-daily attacks continue year after year without a break.

Episodic cluster headache can turn into chronic cluster headache, and *vice versa*.

What are the symptoms of cluster headache?

There are a highly recognizable group of symptoms. Most importantly, cluster headache is excruciatingly painful. The pain is strictly one-sided and always on the same side (although in episodic cluster headache it can switch sides from one episode to another). It is in, around or behind the eye and described as searing, knife-like or boring. It becomes worse very quickly, reaching full force within five to 10 minutes, and when untreated lasts between 15 minutes and three hours (most commonly between 30 and 60 minutes). In marked contrast to migraine, during which most people want to lie down and keep as quiet as possible, cluster headache causes agitation. People with this condition cannot keep still – they will pace around or rock violently backwards and forwards, even going outside.

Also, the eye on the painful side becomes red and waters and the eyelid may droop. The nostril feels blocked, or runs. The other side of the head is completely unaffected.

What causes cluster headache?

Despite a great deal of medical research into the cause of cluster headache, it is still not known. Much interest centres on the timing of attacks, which appears to link to circadian rhythms (the biological clock). Recent research has highlighted changes in a part of the brain known as the hypothalamus, the area that controls the body clock.

Many people with cluster headache are or have been heavy smokers. How this may contribute to causing cluster headache, if it does, is not known. Stopping smoking is always a good thing for health reasons, but it rarely has any effect on the condition.

What are the triggers?

So-called *triggers* set off a headache attack. Alcohol, even a small amount, may trigger an attack of cluster headache during a cluster episode but not at other times. We do not understand how this happens. There do not appear to be other common trigger factors.

Do I need any tests?

Because of its set of symptoms, cluster headache is easy to recognize. There are no tests to confirm the diagnosis, which is based on your description of the headaches and other symptoms and the lack of any abnormal findings when your doctor examines you. Therefore, it is very important to describe your symptoms carefully.

If your doctor is not sure about the diagnosis, tests including a brain scan may be carried out to rule out other causes of headaches. However, these are not often needed. If your doctor does not ask for a brain scan, it means that it will not help to give you the best treatment.

What treatments are there?

There are a number of treatments for cluster headache which often work well. They all need a doctor's prescription. The most usual treatments for the attack are 100% oxygen, which needs a cylinder, high-flow regulator and mask from a supplier, or an injected drug called sumatriptan, which you can give to yourself using a special injection device.

Preventative medications are the best treatments for most people with cluster headache. You take these every day for the length of the cluster episode to stop the headaches returning. They are effective, but you do need rather close medical supervision, often with blood tests, because of the possible side-effects. You may be referred to a specialist for this. The referral should be urgent because, if you have this condition, we know you are suffering greatly.

What if these don't work?

There are a range of preventative medications. If one does not work very well, another may. Sometimes, two or more are used together.

What can I do to help myself?

Ordinary painkillers do not work – they take too long, and the headache will usually have run its course before they take effect. For effective treatment, you will need to ask for medical help. Do this at the start of a cluster episode, as treatment appears to be more successful when started then.

Keep a diary

You can use diary cards to record a lot of relevant information about your headaches – how often you get them, when they happen, how long they last and what your symptoms are. They are valuable in helping with diagnosis, identifying trigger factors and assessing how well treatments work.

Will my cluster headache get better?

Cluster headache may return for many years. However, it seems to improve in later life for most people, particularly those with chronic cluster headache.

For more information, visit www.i-t-b.org