

CLUSTER HEADACHES

A note for those who know a C.H. sufferer
www.clusterheadaches.com.au

Someone has probably given you this note to explain a little about a condition they suffer from called **cluster headaches**. It is likely that before you met them, you had never heard of this condition, which, after all, affects fewer than 1% of the population. 69 in 100,000. Men are more frequently affected than women, probably by around 3 to 1.

Because it is so rare, sufferers often feel isolated, especially through misunderstanding by those who do not fully appreciate its effects. This short explanation, written by a fellow sufferer, is intended to help with that.

What is it?

It is a neurological condition which manifests itself as **extreme** pain, on one side of the head. It is frequently accompanied by some or all of:

- tearing in the eye,
- runny/blocked nose,
- changes in the pupil of the affected side,
- sweating

The attacks are relatively short (2-3 hours), with a very rapid onset. They tend to occur several times a day, There are two types of the condition, **episodic** and **chronic**. In the episodic form, the attacks occur in a bout lasting several weeks (8 – 12), after which they disappear for around a month. This is where the name **cluster** headache comes from. Chronic sufferers do not get this relief, and their attacks can continue daily for many years (25 or more is not unknown).

A curiosity of C.H. is that both the individual attacks and the clusters themselves can have an almost metronomic regularity - attacks starting at a precise time of day is typical

It **is** a headache, in that the pain is in the head, but that is really where the similarity ends. The name itself leads to confusion, as people immediately think of it as something that can be cured by taking a pill, or by thinking of it as a migraine. As one who has had both conditions, clusters are **nothing** like migraine.

Those bald facts, though, do not do justice to the pain experienced. It is stated, by neurologists who deal with the condition, to be **the most severe pain experienced by human beings** - certainly female sufferers say that it is more painful than childbirth. Try and imagine giving birth three or more times a day, possibly for several years, and you may get some idea of what it is like. A more sinister name for it is suicide headache - for obvious reasons. More than half of all sufferers have considered this, and, sadly, I know of at least three who have been driven to it in the last eighteen months.

How is your friend/colleague affected?

This will vary enormously. Sufferers are reluctant to allow anyone else to see them at that point, I suspect for three reasons. First, with family and friends, it is simply to avoid them having to see something which, as they are

powerless to help, is very upsetting. Second, no-one is keen to be seen in a state where they will scream, cry, pace, hit their head repeatedly and generally be uncontrollable - dignity does matter. (I heard from someone recently who went to their local hospital, where they were not treated with medication, but in fact institutionalised for three days because of their extreme behaviour.) Finally, coping with the attack is wearing in the extreme, and having to cope with other people around is just not possible for most.

In addition, the cumulative effects of repeated attacks, and the medications used, can lead to tiredness, irritability, and an occasional loss of temper (particularly when it is suggested that things can't possibly be that bad). Depression is quite common. Some individuals lose their jobs, and even partners and homes, as a result of C.H. That said, because having to cope is part of the nature of the condition, most sufferers will "get along" - they have to be quite strong to survive.

Most can be helped by medication, but, because the cause of the illness is unknown there is no cure. Those on medication take (generally large quantities of) pain-killing and preventative drugs. These often mask or reduce the symptoms, but, to my knowledge, never remove them.

It should be noted here that *doctors* are often poorly informed about C.H., and misdiagnosis is very common. Some GPs are reluctant to prescribe certain drugs, even when they are known to be effective.

What can you do to help?

When an attack hits, nothing. The best thing is to stay well away. Afterwards, a quiet word is probably a good idea. You may find the sufferer will talk about what he goes through if you ask - he may appreciate the opportunity to explain.

If you are interested, you might like to visit www.clusterheadaches.com.au where your friend is probably a member.

Things to avoid saying/doing

Most sufferers are happy to discuss how things affect them, and how you can best help them, but you will find your conversations very short if you say any of the following:

"I had one of those once" - no-one ever has **one** cluster headache

"My aunt has migraine too" - migraine is nothing like C.H.

"Can't you just take a tablet and lie down?" - no is the answer, most sufferers **cannot** lie down during an attack

"Just pull yourself together and work through it" - suggest that, and step back several paces!

This is not rudeness, but simply the result of experience. Sufferers know that sometimes it is simply better to ignore remarks such as these and leave the person in ignorance. If you have read this far, though, that probably doesn't apply to you!

Cluster headaches. Cluster headaches, named for their repeated occurrence over weeks or months at roughly the same time of day or night in clusters, begin as a minor pain around one eye, eventually spreading to that side of the face. The pain quickly intensifies, compelling the victim to pace the floor or rock in a chair. "You can't lie down, you're fidgety," explains a cluster patient. "The pain is unbearable." Other symptoms include a stuffed and runny nose and a droopy eyelid over a red and tearing eye.

Cluster headaches last between 30 and 45 minutes. But the relief people feel at the end of an attack is usually mixed with dread as they await a recurrence. Clusters may mysteriously disappear for months or years. Many people have cluster bouts during the spring and fall. At their worst, chronic cluster headaches can last continuously for years.

Cluster attacks can strike at any age but usually start between the ages of 20 and 40. Unlike migraine, cluster headaches are more common in men.

Studies of cluster patients show that they are likely to have hazel eyes and that they tend to be heavy smokers and drinkers. Paradoxically, both nicotine, which constricts arteries, and alcohol, which dilates them, trigger cluster headaches. The exact connection between these substances and cluster attacks is not known.

Despite a cluster headache's distinguishing characteristics, its relative infrequency and similarity to such disorders as sinusitis can lead to misdiagnosis. Some cluster patients have had tooth extractions, sinus surgery, or psychiatric treatment in futile efforts to cure their pain.

Other research studies have turned up several clues as to the cause of cluster headache, but no answers. One clue is found in the thermograms of untreated cluster patients, which show a "cold spot" of reduced blood flow above the eye. The cause of cluster headaches is unknown. They may be genetic, since people whose parents or siblings have cluster headaches are at more risk for developing them.

Cluster headaches may be caused by a problem in an area of the brain called the hypothalamus. This area of the brain seems to be more active in people who have cluster headaches. The hypothalamus is a region of the brain that regulates sleep cycles, body temperature, pituitary gland activity, and other autonomic nervous system functions.

When the hypothalamus malfunctions, thyroid problems, cluster headaches, and sleeping, eating, or reproductive problems may result.

The sudden start and brief duration of cluster headaches can make them difficult to treat; however, research scientists have identified several effective drugs for these headaches. The antimigraine drug **sumatriptan** can subdue a cluster, if taken at the first sign of an attack. Injections of dihydroergotamine, a form of ergotamine tartrate, are sometimes used to treat clusters. Corticosteroids also can be used, either orally or by intramuscular injection.

Some cluster patients can prevent attacks by taking **propranolol, methysergide, valproic acid, verapamil**, or lithium carbonate.

Another option that works for some cluster patients is rapid inhalation of pure oxygen through a mask for 5 to 15 minutes. The oxygen seems to ease the pain of cluster headache by reducing blood flow to the brain.

In chronic cases of cluster headache, certain facial nerves may be surgically cut or destroyed to provide relief. These procedures have had limited success. Some cluster patients have had facial nerves cut only to have them regenerate years later.