



CLUSTER HEADACHE SYNDROME

A note for those who know a C.H. sufferer:

Why should I read this?

Someone you know has probably given you this note to explain a little about a condition they suffer from called Cluster Headache Syndrome. It is likely that before you met them, you had never heard of this condition, which, after all, affects less than 1% of the population.

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

What is it?

The term "headache" is very misleading. Your friend or coworker is not experiencing the typical symptoms of familiar primary headaches, such as Migraine and Tension. Cluster Headache (CH) has a prevalence of approximately 69 cases per 100,000 people, although it may be much higher. The cause and cure of Cluster Headache Syndrome are unknown. Cluster Headache sufferers fall into two categories: Episodic and Chronic. Episodic sufferers experience headaches in clusters for a period of typically six weeks to six months and will go into periods of remissions typically lasting from six months to 3 years. Chronic sufferers experience no periods of remission lasting longer than two weeks in the period of one year.

A CH attack is unilateral (one sided). Pain may begin around one eye, "Like a nail or knife stabbing and piercing" the eye, or as if someone "were pulling out" your eye. It may be accompanied by a tearing or bloodshot eye, drooping eyelid, dilated pupil and nasal congestion or runny nose on the side of the attack. It can radiate from the eye to the forehead, temple, ear, cheek, jaw and neck on the same side. The pain of a CH has been described as piercing or boring and so excruciating that most victims cannot sit still and feel compelled to rock in a chair, walk back and forth, or bang their heads against something. The pain is so extreme that Dr. Peter Goadsby, Professor of Clinical Neurology at University College, London, and the world's leading researcher on CH has commented, "Cluster headache is probably the worst pain that humans experience. I know that's quite a strong remark to make, but if you ask a cluster headache patient if they've had a worse experience, they'll universally say they haven't. Women with cluster headache will tell you that an attack is worse than giving birth. So you can imagine that these people give birth without anesthetic once or twice a day, for six, eight or ten weeks at a time, and then have a break. It's just awful." Most CH victims experience these attacks 2 to 10 times daily. The pain quickly escalates from no pain to unbearable pain within five minutes. The pain subsides in the same manner. Attacks can last anywhere from 30 minutes to 3 hours or more.

Those bald facts, though, do not do justice to the pain experienced. A more sinister name for a CH is “suicide headache” - for obvious reasons. More than half of all sufferers have considered this.

A curiosity of Cluster Headache Syndrome is that both the individual attacks and the clusters themselves can have an almost metronomic regularity - attacks starting at a precise time of day are 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.

CH sufferers experience some of the most intense pain known to the medical field. There are many medications available to help CH patients manage their condition. Medications fall into three categories: **Preventive** (medications which are used to abort the cycle, such as steroids, Verapamil, Lithium, etc.) **Transient** (medications used to help while the preventatives take effect, such as Prednisone and other steroids), and **Abortive** (medications which are used to abort the headache, such as Imitrex, oxygen, etc.)

Narcotic medications are not recommended as effective management for cluster headaches.

How is your friend affected?

This will vary enormously, and, surprisingly, you will almost certainly never witness a full-blown attack. Seeing someone in that state can be quite terrifying. Sufferers are reluctant to allow anyone else to see them at that point, for three main 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; and three, 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 CH. 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. The medications often mask or reduce the symptoms, but do not remove them.

It should be noted here that *doctors* are often poorly informed about Cluster Headache Syndrome 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, there is nothing anyone can do, unless the sufferer requests help. 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. Sympathy will be appreciated, certainly, and, if you are working with someone, make sure that you do not give any reason for them to think that you blame them for the inconvenience they may have caused. Most will be keen to get on with things, and repay any efforts you have made to cover for them, if the nature of the work allows.

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 a CH.

“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!

More information

To learn more about this disorder, you may wish to visit the following links:

O.U.C.H.

<http://www.ouch-us.org>

New England Center for Headaches

<http://www.headachenech.com/> or <http://www.headache.net>

Cluster Headaches

<http://clusterheadaches.com>

Michigan Head/Pain & Neurological Institute

http://www.mhni.com/faqs_cluster.html

The National Headache Foundation

<http://headaches.org/educationalmodules/completeguide/cluster.html>

Thank you for supporting your friend. This can be a very frightening disease and your encouragement and understanding is an important and vital factor in helping to manage CH.

Original draft of this letter written by Simon Bower for <http://www.clusterheadaches.org.uk>