

## CLUSTER HEADACHES

A note for those who work with a C.H. sufferer

### Why should I read this?

Someone you work with 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 less than 1% of the population. 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, with a very rapid onset, normally subsiding after about an hour, if not treated with drugs. They tend to occur several times a day, most frequently waking the patient in the early hours. There are two types of the condition, **episodic** and **chronic**. In the episodic form, the attacks occur in a bout lasting several weeks, after which they disappear. 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 (I can almost set my watch by the 2.15am attack).

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, and, surprisingly, you will almost certainly never witness a full-blown attack. I know from experience with my own family that seeing someone in that state can be quite terrifying. 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. (Recent research points to an abnormality in the hypothalamus - an area of the brain.) Those on medication take (generally large quantities of) preventative drugs. These often mask or reduce the symptoms, but, to my knowledge, never remove them. When an attack occurs, it can be treated most effectively by breathing pure oxygen or injections of sumatriptan.

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. In the UK the situation is variable, and I know I am fortunate in that my attacks are always short due to doctors who are prepared to give me the medications I need. In the States, because of the insurance aspect of drug provision, the situation seems far worse, many patients having to do without effective medication at all. I know I could not cope with that.

### **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. 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.

If you are interested, you might try visiting the web site [www.ouchuk.org](http://www.ouchuk.org) - home of the charity OUCH (UK) - this will give you a better idea of things than this information sheet can possibly do. For those outside the UK [www.clusterheadaches.com/](http://www.clusterheadaches.com/) or [www.clusterheadaches.org/](http://www.clusterheadaches.org/), provide content with a more North American emphasis, and there are other OUCH sites appearing throughout the world.

### **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!

*Simon Bower, Staffordshire UK, June 2000*