

## ***PAIN SO SEVERE, YOU JUST WANT TO DIE...***



This is one sufferer's graphic illustration of what a Cluster Headache attack feels like. Although estimated to be around the same number of Cluster Headache sufferers in the UK as there are sufferers of MS, hardly anyone has heard of our condition and most people afflicted with this devastating disease are struggling on alone and isolated with their pain.

What is CH? It's a rare neurological disease estimated to affect less than 0.5% of the population, with men being more prone than women. The pain is absolutely excruciating, affecting one side of the head and face. It is described by one leading Neurologist as being the most severe pain experienced by mankind. Women say that each attack is far worse than childbirth (try and imagine giving birth between 1 and 6 times a day - every day, for months on end - and you have some idea of the pain of CH).

Because Cluster Headaches are so rare, it is not unusual for sufferers to be mis-diagnosed for many years and incorrectly/ineffectively treated for such conditions as migraine, severe neuralgia, chronic sinusitis, ear infections, and eye or tooth/root canal problems.

The cause of Cluster Headache is not known and there is no cure. It can begin at any age (our youngest member is one, our oldest is eighty) and it is a life long condition. Our aim is to reach as many sufferers and healthcare professionals as we can across the country to educate them on the symptoms of CH and to let them know that help, advice and support is available through the Charity, OUCH UK (Organisation for Understanding of Cluster Headache).

The medical term 'headache' for this condition is something of a misnomer. Whilst sufferers do experience 'piercing' or 'stabbing' pains in the side of the head, the worst of the pain is normally concentrated in the eye on the affected side of the face, often radiating down into the cheek, ear, jaw and upper teeth. Symptoms include excessive watering, swelling/redness of the eye and drooping of the eyelid.

Totally the opposite to migraine, sufferers with CH are unable to lie down or remain still during an attack and will pace and 'dance' around from one foot to another, or rock violently back and forth. Profuse sweating and raised temperature often accompanies the pain, as does either a runny nostril/blocked nostril on the affected side. Not all sufferers will experience all of these symptoms, but invariably they will experience an attack (or attacks) at practically the same time each day, and most will be awakened by the pain within a couple of hours of falling sleep. Once correctly diagnosed by a Neurologist, there are a number of preventive and/or abortive medications that can help a CHer cope better.

There are two types of CH – 'Episodic' and 'Chronic'. If you are an Episodic sufferer you may have a period of many weeks - or months - of between 1 and 6 attacks every day, each lasting anything from 45 mins to 3 hours: the condition then goes in to remission and you can have months or even years free from the pain. A Chronic sufferer does not get remission periods and can experience these painful daily attacks month after month, year after year (25 years or more is not uncommon). Anxiety, depression, dejection and irritability are all side effects of the pain and continual lack of sleep. Many CHers lose their jobs, their homes, their families as a result of Clusters.

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