

OUCH (UK) can help

OUCH (UK) is the UK's only dedicated expert patient group focused on supporting those with Cluster Headache. Its patron and chairman is Professor Peter Goadsby, world-renowned authority on Cluster Headache currently based at King's College hospital in London.

The charity originated in Professor Goadsby's NHS clinic when a group of Cluster Headache patients chatted while they were waiting to be seen. Then through a former website called Cluster Headache UK, founded by sufferer Simon Bower, it was decided to form a charity. This was formally registered in 2002 with the name 'Organisation for the Understanding of Cluster Headache', or OUCH (UK).

Sufferers are not alone.

OUCH (UK) provides a warm and supportive community in which to interact with others who truly understand.

Sufferers can feel isolated and desperate, and that no-one can understand the excruciating level of pain they endure. But they are not alone. OUCH (UK) does understand: the charity is run by sufferers for sufferers and provides advice and support to them, their families and even their GPs.

www.ouchuk.org

A Charity Registered in England 1091919



OUCH (UK) provides:

- A vital telephone and email Advice Line, helping sufferers to find medical support, treatment and sources of advice on employment rights and disability benefits
- an online forum and social media presence, where sufferers can talk and learn from one another
- an informative website with news and research updates
- conferences where sufferers can get together, meet and hear talks by medical professionals, ask questions and make contacts
- liaison with medical and healthcare professionals to increase awareness of Cluster Headache and to promote OUCH's role in supporting sufferers
- leaflets, booklets and a newsletter
- increase in public awareness of the condition
- links to Cluster Headache sufferers for researchers into the causes, treatments and cure for the condition
- a shoulder to lean on when times are bad

Join OUCH (UK)

at www.ouchuk.org



Advice Line: 0800 6696824

Email: advice@ouchuk.org

Messaging service available 24 hours a day, 7 days a week. Calls returned within 24 hours by our trained Advice Line team.

General enquiries: info@ouchuk.org

Correspondence address:

OUCH (UK), PO Box 62, Tenby, SA70 9AG

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OUCH^{UK}

Organisation for the Understanding of Cluster Headache

CLUSTER



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HEADACHE?

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What is Cluster Headache?

Cluster Headache is a rare neurological disorder estimated to affect under 0.2% of the population. Sufferers have daily attacks of excruciating pain centred around one eye, between one and 8 times a day. Each attack can last from about 45 minutes to three hours, often at the same times of day and night. The attacks frequently occur at night and sufferers will be awakened within a couple of hours of falling asleep.

The pain has been described by sufferers and leading neurologists as one of the most severe pains known.

Women say that each attack is worse than childbirth, and sufferers are brought to their knees, sobbing in agony. Anxiety, depression and sleep deprivation are side effects of the pain and sufferers live in dread of the next attack.

Sufferers can lose their jobs, homes and families as a result of this condition.

Many sufferers will at least contemplate if not actually attempt suicide because of the severity and constant repetition of their pain.

It is vital for sufferers to be seen as quickly as possible by a neurologist specialising in headache.

Once correctly diagnosed, there are a number of preventative and/or abortive medications that can help control the condition.

The medical term 'headache' is something of a misnomer. While sufferers do experience piercing or stabbing pains on the affected side of the head, the worst of the pain is normally concentrated in the eye on the affected side, often radiating down into the cheek, ear, jaw and upper teeth.

Unlike with migraine, Cluster Headache sufferers are unable to lie down or remain still during an attack. They will pace around or rock violently back and forth.

The pain is often accompanied by excessive tear production, swelling and redness of the eye and drooping of the eyelid. There is often profuse sweating, raised temperature, and a blocked or runny nostril on one side.

Not all sufferers will experience all of these symptoms, but they all experience daily attacks of excruciating pain, usually at the same times each day, and most sufferers will be awakened by the pain during sleep.

OUCH has developed a handy questionnaire

"Do I Have Cluster Headache?"



<https://ouchuk.org/do-i-have-ch>

There are two types of Cluster Headache

An **Episodic** sufferer has recurring periods of these agonising attacks happening every day for weeks or months at a time. The condition then goes into remission for a period and there can be months or even years free from pain.

A **Chronic** sufferer does not have remission periods and can experience these daily attacks of pain every day, month and year.

The cause of Cluster Headache is not known. It can begin at any age and is a lifelong condition.

It is estimated that there are around the same number of Cluster Headache sufferers in the UK as there are sufferers of Multiple Sclerosis (MS). However, the condition is not well known and many sufferers are struggling on alone with no adequate diagnosis or treatment.

It's not unusual for them to be misdiagnosed for many years and wrongly treated for conditions such as migraine, sinusitis, ear infections, neuralgia, eye or dental problems. They very often have a long and stressful journey to get the right diagnosis and treatment.



You are not alone