

Detailed description of cluster headaches to help employers, doctors, patients and those that do not understand this serious condition

Conceptual paper

Imagine, your eye is being pried out of its socket with a screwdriver jammed through your temple. The eyelid above that eye is beginning to swell shut. You start squinting, the eye is tearing and your nostril is running like a faucet. You are convinced there is blood pouring out of your head.

The red-hot screwdriver is crushing into your temple and into the eye, causing excruciating, horrible, horrible pain, and there's no way to escape it. Sleep is impossible, so you pace from room to room, dance the cluster two-step in little circles, cry out in anguish, bang your head with your fists, fling yourself to the floor or rock in a fetal position until eventually the pain drains from you. The first few attacks come out of nowhere. You don't know what's happening, but you're convinced an artery in your brain has ruptured and death is only minutes away.

Waiting for the next attack to happen is a terrible, scary feeling loaded with fear and anxiety. Some think it only happens at night... Not true... Day or night attacks happen usually the same time every day and night unless an attack is triggered by several possibilities. Sleep, when it is possible after an attack, is another source of fear. You know the attacks hit within the first hour of sleep so you sit there all night afraid to lay down sometimes for days or longer making sleep deprivation a factor with this disorder. Some think they will go mad sitting there exhausted until the next attack hits and the terrible pain starts all over again.

The really tragic story is too many cluster headache sufferers experience these terrible attacks for years before being correctly diagnosed. The cluster headache disorder has a prevalence of less than one tenth of one percent so even most neurologists are unfamiliar with the cluster headache syndrome so assume it's some form of migraine after ruling out actual brain abnormalities with an MRI and in fact cluster headaches and migraines are two distinctly different disorders.

Over the counter pain medications are useless and many, especially NSAIDS like Ibuprofen, aspirin, tylenol, excedrin etc. cause rebound headaches (Medication overuse headaches) and can start a brutal vicious cycle of more attacks, more powerful attacks and more frequent attacks. Powerful opiates dull the pain, but cannot stop the attacks and are not recommended for cluster headaches.

Opiates can give some relief, but can cause rebound headaches as well and actually make them more painful and being highly addictive may just make the situation worse. Many cluster headache sufferers rate the pain of their attacks on a 10-Point Headache Pain Scale developed by "Kip" Kipple, a long time cluster headache sufferer.

A Kip-1 cluster headache is minor, but they rarely stay at this pain level escalating to a Kip-7 in less than a minute. A Kip-10 cluster headache is the most extreme. When the pain gets to a Kip-10, sufferers head for the Emergency Room. Many cluster headache

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sufferers contemplate suicide after weeks, months or years of daily attacks numbering 3 to eight or more a day at this pain level as it can be for many patients just unbearable.

The video link below illustrates Chuck Setzco, a.k.a. "ClusterChuck" experiencing a classic cluster headache attack. He's using oxygen therapy at a flow rate of 15 liters/minute with a non-rebreathing oxygen mask. However flow rates this low are largely ineffective at the higher pain levels and it took 25 minutes to abort this attack.

Oxygen flow rates that support hyperventilation, (25 to 40 liters/minute) or an oxygen demand valve are far more effective at aborting cluster headaches at the higher pain levels. Many sufferers average 7 minute abort times using this method of oxygen therapy.

The cluster headache syndrome is characterized by a circadian rhythmicity with the terrible attacks occurring from three or four times daily to over twelve times a day for some patients and lasting from 15 to 180 minutes. The attacks are characterized by strictly unilateral severe head pain in and around the eye on the affected side. They are accompanied by autonomic symptoms, swelling eyelid, tearing, and running nose. Some cluster headache sufferers also experience cutaneous allodynia, where the skin of the face and scalp on the affected side of the head becomes extremely painful with the lightest touch.

Episodic cluster headache sufferers experience clusters or bouts of these daily attacks starting from 6 to 8 weeks or much longer in duration up to 335 days per year and still be called "Episodic" followed by a remission period varying in length. Many have their attacks start at the same time each year. Chronic sufferers experience these daily attacks and as the chronic description goes having these horrific attacks daily without more than thirty days of relief within a year.

Cluster headache is a stereotyped primary pain syndrome characterized by strictly unilateral severe pain, localized in or around the eye and accompanied by ipsilateral (same side) autonomic features.

The syndrome is also characterized by the circadian rhythmicity of the short-lived attacks, and the regular recurrence of headache bouts, which are interspersed by periods of complete remission in most individuals.

Headaches often start within 1–2 hours or less after falling asleep or in the early morning, or daily occurring about the exact same time and show seasonal variation, suggesting that the hypothalamus (circadian body clock) has a role in the illness. These seasonal variations with a lower frequency of attacks coming in the mid summer months also suggest the seasonal variation in vitamin D3 serum levels may play a significant role in the pathogenesis of this disorder.

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Conflicts of interests

The authors disclose no conflicts of interest.