



Cluster Headache Support Group, Inc.
P.O. Box 21
Fountainville, PA 18923
(785) 330-5108
www.chsg.org

Dear loved one,

Your loved one has given you this note to explain the neurological disorder called **Cluster Headache**. Very few people know of this disorder. Cluster Headache is a rare condition, only affecting every 1 in 1,000. Because it is so rare, it can be difficult to find the right medical treatment. Patients often go years misdiagnosed and suffering without proper treatment. Sufferers often feel isolated, too. Isolation occurs because many (even doctors) misunderstand the disorder. Many underestimate the impact this disorder has on everyday life.

This letter is an attempt to clear-up some of the confusion. Also included is a description of Cluster Headache from The Lancet.

What is Cluster Headache?

1. The word "headache" is the only similarity between Cluster Headache and the other headaches you know about. They are nothing like a migraine or tension headache. They are not caused by stress, bad food, or poor body posture. Please refrain from offering treatment advice.
2. "Episodic" sufferers will have a period that lasts several weeks and then recurs again in a few months or years. "Chronic" sufferers are "in cycle" constantly, without remission.
3. An attack will reach devastating pain levels on one side of the head within a few minutes, so quick action is essential.
4. Attacks can last from 15 minutes to 3 hours and occur several times a day, often on schedule every day ("in a cluster") during a period. Often attacks occur in the middle of the night and disrupt sleep.

How is your loved one affected?

1. When an attack occurs, he or she may cry or wail uncontrollably. Your loved one might not respond to question or comments. Brief, one-word answers may be expected, at best.
2. Your loved one may pace or rock in place and act out of character. The pain of a Cluster Headache attack is one of the worst pain experiences known. It is worse than amputation, childbirth, kidney stones, or even a gunshot wound.
3. One eyelid may droop or close shut. The eyes may tear up and become red and/or swollen. The face may sweat or become flushed. Nasal congestion, runny nose, and nausea are also common.

How can you help?

1. During the attack, give him or her lots of space in a private location. Calling 911, unfortunately, will not help. Attacks usually resolve within 15 minutes to 3 hours. If prescribed, your loved one may use injectable sumatriptan, high-flow oxygen, or both. Other acute treatments may be prescribed by his or her doctor.
2. After the attack, offer some water and a quiet place to rest. Do not rush your loved one back into regular activities as he or she will feel exhausted and need time to recover.
3. Refrain from offering advice or comparing Cluster Headache to migraine or other headaches. This is a completely different condition requiring very different treatment. It is not brought on by poor diet, stress, or eye strain. The cause is unknown, although researchers think that dysfunction of the body clock (hypothalamus) may be involved.

Thank you for taking the time to read this information. Should you have additional questions about Cluster Headache, feel free to visit our website at <http://www.chsg.org> to learn more.

Yours truly,

The CHSG Team