

Understanding this disorder

Conceptual paper

The first documentation of the cluster headache patient group dates back to 1641, it would be another hundred years before the founder of the Vienna School of Medicine, Dr. Gerhard Van Swieten gave an overall description of a case of episodic cluster headache. Not until 1926 was the first complete description of the disease done.

“Cluster Headaches”. Aka “Suicide Headaches” The name cluster headaches do absolutely no justice to this rare, severe and incredibly painful neurological disorder that affects about 0.1% of the population (about the same as multiple sclerosis).

It affects men, women, children, even toddlers and suspected in infants on every continent on the planet and being 7,090,372,979 people here as of June 2013 cluster headache patient number over 7 million. It is also said that more men than women get CH but that figure is changing constantly because of migraine, believed to affect more women than men and are many times misdiagnosed.

Cluster headaches can be “episodic” or “chronic”. Episodic meaning the patient will get periodic remissions varying in length. You can still be considered episodic, even if you have daily attacks up to 335 days per year and as everyone is different so are the length of their cycles.

One thing for sure is when in cycle sufferers with episodic cluster headaches has that sickening feeling of not knowing when the attacks will start or end causing severe anxiety. Depression is also a serious problem. Chronic cluster headaches are defined as going a whole year without more than thirty days of relief which speaks for itself. Either Episodic or Chronic both is the same pain and are seriously disabling...

Some patients get up to or more than a dozen attacks daily or back to back attacks. Attacks last from fifteen minutes to three hours each, day or night and is the most painful disease of any known to medical science.

To quote Professor Peter Goadsby a long time neurologist, researcher and leader, considered the very best in the field of cluster headaches and primary headache disorders... “More painful than childbirth without anesthetic, migraine headaches, burns, gunshot wounds, knifing, broken or shattered bones, renal colic, kidney stones or a limb amputated without anesthetic”. This information comes directly from sufferers and compiled by Prof. Goadsby and the medical field from many thousands who have endured these different situations and have cluster headaches.

Suggesting the words to a cluster headache patient to “just take some aspirin and lay down” can be very frustrating. Over the counter medication is practically useless and is not recommended for cluster headaches. They can cause rebound headaches (Medication overuse headaches) and actually make cluster headaches worse. Laying down in most cases makes them worse too. Narcotics also are not recommended to treat a cluster headache and can be a serious problem for many reasons.

There are new alternative preventive treatments using Tryptamines that are having great results (see www.clusterbusters.org) and high

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flow oxygen at a flow rate of 15 to 25+ Lpm (Liters per minute) as an abortive can stop an attack in as little as 5 minutes and is the number one abortive for CH but as we are all different it does not work for everyone. Many do not do the treatment properly to achieve the best response.

You must breathe it to support hyperventilation or in other words, breathe as much as you can as fast as you can without passing out. Once a cluster headache has started and if not treated within the first ten minutes it is very difficult to stop an attack. An attack can cause the patient to literally smash their head into the wall or floor, scream and cry or pull their hair out, make them rock back and forth, hit their head and faces with a closed fist.

One thing you do not want to do during an attack or anytime really is massage the Carotid and or Temporal arteries (See illustration above) if massaged it can loosen plaque or deposits causing the possibility of a stroke, fainting or in extreme cases, death. Try not to focus your massage in those specific areas of the side of the head... Safety first...

Some describe it as a knife or screwdriver in their eye through their brain being hammered in and out and while in an attack, it makes you desperately try to pull this phantom knife out as it is the literal, physical feeling of that knife. Unlike migraine it causes the patient to feel the need to move constantly v's lying down in a dark room.

They have been given the name “Suicide Headaches” for a very profound reason and many patients have been lost to this horrific condition. Far more prevalent, if not just as devastating, is the tremendous erosion of quality of life manifested through the loss of jobs, family and friends, etc. This combined with Post Traumatic Stress Disorder (PTSD) which has been associated with cluster headaches, combined with severe anxiety, depression and the unbearable pain and isolation, is believed to be the reason why the suicide rate among patients is so high as the rate is 20 times the national average for suicide.

Knowing that the pain may never end for chronic patients and the fact that a new cycle will surely begin for episodic patients. It truly makes it difficult for these people to continue the constant individual powerful battles that are cluster headaches...

“The most painful condition known to medical science” requires humanity to triage this seriously overlooked and underfunded patient group to the forefront of scientific research today!”

I have written this information for you based on the most part of 42 years being a chronic cluster headache patient and several years of study.

Written by John Fletcher with edits from loving cluster headache patients who sincerely thank you all very much for reading this important information...

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Conflicts of interests

The authors disclose no conflicts of interest.