

# Lack of understanding of cluster headache disease

## Conceptual paper

The serious lack of understanding of Cluster Headache disease is profound and the general public still in many cases thinks it is only a headache. That is far from the reality of the situation and it certainly is nothing like the word itself implies. It is considered around the world by professionals to be “The Most Painful Disorder Known To Medical Science” That is what CH is...

One main reason we did this was because of continuing to find and read the same old descriptions that continue to undermine and seriously trivialize this disease.

The other reason is having seen many of the YouTube videos of patients having attacks and read the incredibly cruel, hateful, hurtful & ignorant remarks, saying they should “get an academy award” or “you know they are faking” Or being a “Drama Queen!”

Every single video we have seen are 100% true and the amount of screaming pain you see is also normal and very common during a bad attack and we all get them.



A world of such desperation, depression, anxiety, fear, severe violent pain, suffering and death that I see and hear so often, but almost no one realizes this war going on behind the scenes...

Being a chronic patient myself since 1973 I can say and assure anyone that these following videos are real and true attacks as I to get them this bad sometimes much worse and will put me on the floor screaming, crying and wailing. Smashing my head on the wall or with my fists, sometimes passing out from such severe pain and this pain can do this to the strongest man.

I don't care who they are, this is what happens with this disease and as I said very common. It can take a 300 pound linebacker and put him on his knees screaming and crying like a child, begging for help or even death. That also being no exaggeration at all.

The following video is of Andrea and we know for a fact this is no exaggeration at all. She is NOT acting or faking this attack and is very common and what we all go through in a bad attack. Unbearable, terrifying, extremely violent, incredibly brutal and excruciatingly powerful pain. It is just what CH does...PERIOD.

It did bother me that over 40 people thought Andrea was faking, Gave it a “Thumbs Down”! I know for a 100% fact, this is a normal picture of a person having a bad cluster attack.

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I was shocked, but not surprised as I see this often just how much the ignorance certainly abounds when some folks can't understand something as painful as this and that it just can't be true because they have not experienced themselves or think it is just a bad headache which many have had but a cluster is so far beyond the pain of any kind of headache.

As I have explained it is a disease, A Disorder, A Syndrome, but most of all it is no headache in that descriptive sense of the word. There is nothing like a cluster attack... More painful than even severe migraines. To even use the word headache is so misleading and completely false in any sense and so misunderstood. Same for Migraine “Disease” as it should also not be called a headache as well as all the disabling neurological pain disorders.

People can be very cruel when it comes to CH mainly because of that misuse of the word headache and just not understanding the disorder. Most folks can only go on their own experience of pain and you do not just experience a cluster attack as it is a disease of life long proportions for most from when it starts and that can be almost any age. Mine personally started at 14 years old and I am 56 now and still getting daily and nightly attacks being chronic.

I hear many, many cases of it starting even younger, much younger. Being an administrator for a 5400 member CH support group I hear so many stories and so many people with diagnoses that are under 20 years old many in their early teens or younger. I hear considerably more stories of younger ages when it starts and would like to see more research into this.

It is a Disease... You do not just get one or two or even several, some get up to a dozen attacks a day for years when chronic. Either chronic or Episodic for most is a lifelong disease that can start at practically any age, even as young as five years old or younger and has even been thought to be a reason for some cases of the crying baby syndrome or colic etc. The same with migraine in some cases of very young children...

Diagnoses of CH are getting better, but years ago it could take over 10 years to be diagnosed correctly. In my case it started in 1973 when I was 14 and did not get a correct diagnoses for 18 years. I was told I had “Some Form Of “Super Migraine” for the first couple of years, then it was just some rare form of migraine until I diagnosed myself when I first read a description of CH.

These following videos are completely true and it does happen just like they portray. To say things like those people had the audacity to write and comment on a disease, they obviously have zero knowledge or a clue what it is and does to the patients and severe depression that goes with this... The suicide disease.

These facts when watching Andrea suffer so violently far more in these few minutes than anyone other than another CH patient can fathom, then to basically say to this beautiful person in so much pain that she is faking this attack, being a “Drama Queen” Made me cry for her because I know exactly what she was going through...

It just goes to show perfectly the total hurtful, hateful and Cruel stigma we all deal with having a disease with the words, headache attached to it and that in itself has cost lives. The Serious lack of respect, knowledge, compassion and understanding of the general public about CH is profound.

We are working hard daily to help educate the masses about CH and the reality that this is no headache. CH patients live with such lack of respect and understanding that probably every single patient has been told to “Man Up” It’s just a headache, go take some tylenol and lay down” or I have had one of those before and I understand how

you feel” or I have bad headaches too” These kind of statements are hurtful to those who truly suffer from this “Disease”and it trivializes the incredible pain and the raging battle with “The Beast” as we call it...

All patients want is recognition of the seriousness of the disorder and situation, some respect and true understanding of what they fight so hard every day to beat and still have a life of meaning and purpose living with “The most Painful Disorder Known To Medical Science”.

This following video is of two cluster headache patients that I know and are members of groups that I am in and have known them for a few years. Trust me, they are not faking or exaggerating at all, and this is a good example of real and true cluster headache pain during attacks.

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### Conflicts of interests

The authors disclose no conflicts of interest.