

# Cluster headache patients use caution aborting multiple daily attacks

## Conceptual paper

Some cluster headache patients have used high flow oxygen (15 to 40 Lpm) without any luck. Also a lot of folks give up on o2 without using it properly at high flow to the point of hyperventilation with a non-Rebreather mask, but then there are also those it just plain doesn't work for.

That leaves several other abortive's, home remedies as well, the Triptans, Energy drinks, caffeine or whatever you use to try to abort your attacks... Be careful with the Sumatriptan or any Triptan as they can directly affect your heart and respiratory system. Folks can easily fall into the trap because they abort attacks so well and so quickly and that's a very powerful urge to have to fight constantly and when attacks are bad many find themselves overusing these Triptans and can turn into a vicious cycle of rebound attacks as triptans are notorious for rebounds also called medication overuse headaches. Energy drinks are not the safest thing either as daily use can cause problems.

My point is to understand what treatments can do, not necessarily just the ones I mentioned, but whatever you use that may be potentially harmful in short and long term use and learn it well from multiple sources. It is so important that we understand what can happen when using a certain routine to abort multiple daily attacks and then factoring in any other medical problems and medications that combined can cause even more trouble and there is no doubt that what is medically available to us has the potential to cause problems. Work on finding the preventative that will STOP you from having to live on abortive's.

Don't give up and don't be afraid to at least look at the alternative preventative treatments as many are going CH free with long remissions... Be comfortable with the knowledge gained then proceed with more confidence. I went through a period of my CCH when they first started in 1973 and I was eating 200+ extra strength Excedrin every week for years and started when I was 14.

At that time the only other things offered to me were codeine and ergomar and both totally screwed me up and made my CCH much worse, so the only thing that helped but not really was that extra strength excedrin. It would sometimes help abort my attack, but it was making me get 12 to 20+ attacks a day from rebounds or Medication Overuse Headaches which was such a vicious cycle of back to back brutal attacks day and night for many years. Had 3 ulcers and finally stopped. I went through more frozen peas, then the friggin green giant and cases of popsicles...Lol.

I used Niacin because of the body flush and burning feeling 200mg would give me that "Sometimes" it would disrupt an attack, I didn't know again it was something that I shouldn't have taken, but we are desperate and many patients will try anything to abort an attack and that is the main reason I wrote this. There are plenty of abortive methods that could be harmful in long term use or drug interaction problems. When I was completely alone for so many years thinking I was the only one who had these monsters and going 17 years before a

Special Issue - 2016

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**Received:** December 18, 2015 | **Published:** April 06, 2016

correct diagnoses I tried so many things to try and stop the pain and it was just pure desperation.

I was told by the first neurologist that I saw when I was 14 that I had some form of "Super Migraines" and that's what I thought Lol! I was very ignorant, but found out so was everyone else as no one even said the words cluster headaches for 17 years, I thought for sure I was dying for the first couple of years and the doctors I had seen had nothing that helped in fact it all made it worse and being a commercial fisherman all my life being at sea 300 days a year I just decided to live with them and didn't see another doctor for the next 27 years.

One thing I learned about myself and CCH is that I had to take something out of desperation even if it barely helped or gave very brief periods of precious, precious relief. I found myself with those darn excedrin eating them like tic tacs and no idea that I have probably doubled the amount of attacks and making them more powerful and just plain worse. A vicious cycle to be certain and if anyone doesn't believe in medication overuse headaches or (rebounds). I'm here to say they are very real and unbelievably destructive and big PTSD and depression factors.

Very serious situations like mine was what I'm trying to convey and make sure everyone gets it into their education so something like this never happens to you. I have survived these things as a chronic for the most part of 42 years this year, I have tried so many treatments to stop these things now and still nothing the medical field has offered me worked in any way and the reason I had no choice but try alternative methods to stop the attacks. Personally for me it was the best decision I ever made...

Please take the time to add this to your CH education and a good education in CH is just something we all need to do. Learn about everything we use for CH and study until you completely understand the possibilities. I know many of you know exactly what I'm talking about.

Break up routines aborting with Triptans, use it only for the bad attacks as it was not made for clusters but for migraines and migraines are not multiple daily attacks and the triptans were not created to use at that max 12mg daily for any extended period and should not be

used this way. Education is the key to safety and success battling the beast. We need everyone to be safe and cautious in this crazy cluster world we live in, fighting such incredible pain. Much respect to all my cluster brothers and sisters...

### **Acknowledgments**

None.

### **Conflicts of interests**

The authors disclose no conflicts of interest.