

A story of cluster headache pain & caution

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Before finding the support groups...

I was in the worst year at the time of thirty eight years of CCH (Chronic Cluster Headaches). I was getting so many seriously powerful attacks every day and night and it was getting so much worse so fast that I knew my days were numbered...

I had never heard about Medication Overuse Headaches "MOH" and up to this point was pretty naïve, having yet to gain a full education on the disorder and in my personal situation it hit me very, very hard. The fact that it can rear its ugly head even when taking medications at normal prescribed doses... I was enduring these incredibly violent and brutal attacks every time I hit REM sleep or within the first hour of sleep with several more daily and nightly averaging a dozen a day sometimes several more for a solid year. It is a common symptom of CH to have this happen during sleep, just not the incredible power and escalation of all symptoms caused by MOH. These were not the same bad attacks I had for 38 years, These were something else and so much more powerful than I was used to throughout that year. My CCH started in 1973 at age 14, I'm 56 now.

I was completely and utterly terrified to lay down and was actually passing out from some incredibly brutal attacks which had never happened to me before. On one of those I woke up on my kitchen floor and blood was everywhere as I guess I hit my head on the edge of the counter while blacking out getting a huge gash on my head. It was just something I knew I wasn't able to keep doing every day and night and was like nothing I ever felt in all those years of tens of thousands of attacks. It was beyond brutal and had me so scared and in total awe of the power.

They say this is not a deadly disease? I have no idea how anyone can possibly say that as the suicide rate is 20 times the national average and countless lives have been lost throughout the history of this horrific disease. I was getting ready to be one of those statistics and it wasn't the first or last time. Even though this was a very bad situation, it was not the first time just a much worse time. The previous 38 years and what I still deal with today is a struggle beyond imagination, dealing with this every day year round since I was a 14 year old kid. I believe all cluster headache patients have dealt with this or a similar situation in some way with medications and is far more common than realized or acknowledged.

The daily battle with this disease and what all patients deal with this pain and the brutal ungodly symptoms that give this disorder the accurate name suicide headaches. This pain and what it can do for you whether or not the medication makes it worse or not can and does take lives far more than realized is the brutal reality and I can seriously understand the choice to escape this horrific condition. However, I do not condone suicide and feel in most all situations, there are things that can be done to turn situations around or get the help to keep fighting, but do understand how and why we have lost so many to this severe and extreme disorder.

In this nightmare I was locked into trying to lay down and sleep, 95% of the time trying to get some sleep it would wake me in

screaming, crying excruciating agony within 15 minutes to an hour of falling asleep almost every single night for close to a year. So much terrifying fear of getting another of these insane attacks that I got to the point of just giving up and I didn't even attempt to sleep or even lay down for 6 weeks.

My son who didn't realize my situation as I normally hide my attacks and condition from him gave me his laptop and helped me learn how to use it. I was not up until then a computer guy and had rarely ever used one. I had no idea CH support groups existed and after I found them would sit at the computer day and night, passing out from exhaustion constantly refusing to lay down, knowing what would happen and even sitting in my chair these powerful attacks would keep waking me. I had tried everything to sleep without actually laying down, in my lazy boy chair or using a bunch of pillows so I could sleep sitting up and on and on.

I was absolutely, completely and ultimately done. I knew I couldn't keep it up any longer it was plain and simple it was too much for me to handle and complete loss of quality of life and the pain had me screaming day and night. Also going through this after 17 major operations stemming from perforated diverticulitis (hole in my intestine) and full blown peritonitis, which is what ended my career as a ships captain.

Having other forms of severe chronic pain from nerve damage that had me at a constant 7-8 on its own 24/7 365. If I had to choose between going through those 17 major operations again or 2 days of those incredible attacks (average 12 a day) It is easy, I would do the operations and these were brutal operations opening my abdomen. That is how powerful those attacks were and how terrified I was of getting another one.

It all finally came to the point I ended up in the hospital for a week from severe sleep deprivation and fluid gain. I had put on around 30 lbs of fluid during all of this. I had fluid around my heart sack and in my lungs and you could push my skin down anywhere and it would leave a inch deep finger print that would stay for several minutes. I felt I was physically dying and that death was going to be the end result of all of this.

Some may think this is an exaggeration, but actually just the opposite. I am having serious difficulty expressing just how messed

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up this whole situation was. I wanted to die to escape another of these attacks, I couldn't take it anymore, they were so powerful and I know I'm not alone having this horrible scenario of the worst pain known getting even worse because of medications. It even has a name... "Medication Overuse Headache" (MOH) or "Rebound Headaches" I wrote this as a caution to anyone out there dealing with this same or similar situation.

I really didn't realize at all at the time it was these medications doing this to me and it doesn't need to be these medications but can happen with many of them or combinations of the different medications. Looking back and now understanding MOH and its extreme effects I realized because of my symptoms, it's the only thing that could have caused these mega hits I was having and it all started like this shortly after starting a medication called Topamax. The symptoms of the MOH are more attacks, more powerful attacks and more frequent attacks which was spot on for what was happening to me and had happened before just not this extreme.

After about 6 months on this medication my doctor trying to help added a medication called Depakote and that put my chronic cluster headaches into a place I hope I never see again.

Because no medication has been created specifically to treat this disease creates the common situation of having to keep trying the several off label medications to hopefully find one or combination of medications that may bring some relief. MOH is a common situation with cluster headaches and since learning that was the reason I wrote this to help make others aware... It can really take you by surprise.

After I found CH dot com I started reading and hearing from others about this wonderful treatment called the "Vitamin D3 Anti-Inflammatory Regimen" I contacted the man who created it Pete Batcheller (Batch)... Batch and the D3 regimen saved my life and we have been good friends ever since for almost five years now. I have been helping Batch spread the word about this treatment ever since and personally have helped many patients with the regimen achieve great relief or in most cases full remission.

The D3 regimen saved my life as I went totally CCH free in 3 days and stayed that way for a year and a half. It was amazing going from such a horrible situation to no more attacks at all in 3 days was the biggest turning point I ever had in my life by far. I literally had three things I put in front of myself that would have done the job and I still have those 3 things in my drawer to remind me of just how bad things can really get.

I'm sorry if this scares anyone but the facts are we have treatments that work. I also realize we are all different and I know some CHers that absolutely nothing works and I fear for those fellow sufferers... Still, never give up as it may be just around the corner to find the treatment that can stop or greatly relieve this disorder.

The D3 regimen, having been used for well over ten years and based on an online survey going for over three years now with thousands of patients using it has shown it to be around 84% effective at relief or remission, 60% of that figure achieving full remission. No one to my knowledge or Batch's knowledge has ever had to have medical intervention or treatment of any kind because of the D3 regimen, making this one of the safest most effective treatments in CH history.

Even after years and years of searching for the medicine that will bring relief without luck, never give up! Seriously, it took me 38+ years to finally find a medicine that helped and didn't make things worse or just didn't work. I had given up so many times to the other monster "Depression". When you do find the treatment that brings relief or remission, it can be such an incredibly profound thing after searching in desperation for so many years for nothing, then finding it will bring tears of pure joy to your eyes to finally feel that incredibly precious, precious, PRECIOUS relief....

I think that if I was to make a point of all this it would be... Beware of medications that make your CH worse... Beware of MOH... I believe this situation is far more common than realized and I know many others that had a similar situation. It doesn't have to be those medications that do it, but can happen with several other medications, combinations of medications or different scenarios to cause this disorder to escalate to insane proportions... Also we have treatment options with incredible success rates. Don't give up! Education is the key and we all must get a good education.

Finding a support group and meeting the "Family" for the first time is life changing. We have brothers & sisters around the world all dealing with this that can relate to you and your situation that can help you. Just the fact of not being alone anymore can change everything and hope is a very, very powerful thing and not a fleeting glimpse of it either, grab it, hold on to it and do not let go... Being in a support group has incredible power to help yourself and others completely turn their lives around and I see it every day.

For those new to CH, finding the support groups and gaining an education is the key to seriously helping yourself. You will find hope and just being in a support group can cut years of unnecessary pain and suffering and you will have found what it took a lifetime for many. For you old timers beware that even though you think you have seen it all and everything this disease can do... Pretty sure there are many out there who haven't as it took me 38 years of CCH before this situation happened to me to this extreme and I hope to help with this story...

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Conflicts of interests

The authors disclose no conflicts of interest.