

A New Daily Persistent Headache Journey By Alan Kaplan

This chapter begins in the early part of December 2017. I woke up with a headache that just never went away. I didn't realize it was here to stay until it was. I thought that I had a cold, then the flu, then sinus issues, then allergies, then maybe related to my cervical spine issues. I started going to all types of doctors starting in 2018. My primary couldn't figure it out and he was not well versed in headache disorders. Then off to the Allergy specialist, same results, nothing unusual. Then off to an ENT who checked me out thoroughly and had a CT scan of my sinuses that showed nothing unusual, even though I have a history of sinus issues. He put me on antibiotics, antihistamines and Prednisone. I was already on Gabapentin for cervical nerve issues. Then I started going back to a chiropractor to see if it was related to my cervical spine issues.

All through the initial stages of trying to figure out what was going on, I was still working and dealing with daily headaches with various levels of pain associated with it. I kept on going not knowing what to do or even what it was I was supposed to do. I accepted it for what it was, a constant headache and annoyance. Symptoms were tingling/numbness in neck, shoulder, arm; left sided head pain, occasionally went to right or all around; throbbing; nausea; photosensitivity and sound sensitivity; forgetfulness, foginess; and lack of concentration. I also have to share that the family was dealing with my daughter's Alcohol addiction which came to the surface the previous year. So, we had a lot going on, not knowing what effect that was having on my headache issues, my guess it all contributed and something snapped in my head. What I didn't know was that they were going to be with me 24/7. I didn't know what living in chronic pain was going to do to me. I didn't know that I'd have to wear special tinted lenses indoors to hide from the light. I didn't know that my ears would be pounding so much. I didn't know that the pain can have a mind of its own and go wherever it felt like. I didn't know how radically my life was changing. I didn't know what I didn't know. Now I do.

Unfortunately, the annoyance started to get more concerning, pain levels increased across the day, work was getting harder and harder to stay focused on. I started cutting back my regular activities, cancelling planned events with family and friends. Then the first weird event happened. I was at the chiropractor in May of 2018 and was getting some treatment on a machine and all of sudden I started getting numbness on one side of my face and body. I called the nurse in and she got the Dr. who immediately stopped the treatment. He started doing some checks on

me as I mentioned maybe I'm having a stroke, sort of kiddingly. The numbness faded and he sent me home suggesting I go to the ER. So, I went home and had lunch, talked to my wife about what happened and we looked at each other and decided we better get to the ER and make sure I'm OK. They took me right away, started doing all their checks, ordered a scan, blood, etc. Luckily the scan was negative but they decided to keep me for the night for observation just in case. As I am waiting in the ER room, all these Dr's kept coming in and I told them all the same story including what was going on with my headaches. A neurologist finally came by and I got her on board with my story. They ordered MRI scans, an EEG, gave me some meds and sent me home. Still not knowing anything new or a diagnosis. I did know I did not have a stroke, thank you!

This brings us to the first round of medications that a neurologist started me on to see if they can get the headache under control. I was trying to deal with them with over-the-counter meds, and they did absolutely nothing. They started me on Topamax, in my opinion the worst of them. It just made me feel horrible. More numbness, tingling in weird places and isolated places, like my big toe. I had an incident where the tingling actually travelled from there up to my index finger on my right hand. How does this happen? It freaked me out and freaked out my dog who apparently was sensitive to my body. I had an appointment with that neurologist the next day, told her what happened and she was basically OK, that's interesting and had nothing to offer. That was the last time I saw her!

The next couple of months were difficult as pain levels started to increase, I noticed that by the afternoon, things just went downhill to the point of being couch bound for the remainder of the day. I was finally able to locate a headache specialist in my town. My first appointment was in July 2018. What a life saver, she listened, cared about what I had to say and started immediately in trying to get this figured out. I also finally get a diagnosis, **New Daily Persistent Headache**.

Now comes the never-ending trial of medications: preventatives, abortive, CGRP's, meds to help me sleep, anti-psychotics, Botox, nerve blocks, stimulation devices, green light bulbs, pain meds, and so on. I can't even remember everything we tried. Of course, nothing helped. I also tried acupuncture, strain-counter strain treatment and deep tissue and trigger point massage (the only thing that has consistently made me feel better). After all the above, she never gave up, and finally after a year it was time to send me to a well-known headache center where they'd be able to do in-patient care with IV treatments.

Also, during that year, work and social activities continued to be hard to deal with and at times impossible to get through. In March of 2019, I retired from my job, a few years earlier than anticipated, but it was the right decision for all involved.

It's now July 2019 and I'm meeting with one of the top headache doctors available. I went through all the intake paperwork, met with nurses, a psychologist and the doctor. Pretty much confirming my diagnosis and we decide to pull out the stops and go for the in-patient IV protocols in August. This is DHE and Lidocaine with a bunch of other meds mixed in. I go in without a predetermined number of days I'd be there. It ended up being 7 days. Not fun, but it seemed that something was actually working and pain levels started to go down. Perhaps there is hope after all. I check out a list of meds to take when I get home for preventive or abortive. DHE shots and spray, benztropine, mexiletine, haloperidol, clonidine. I'm now off and running feeling like I might get things back to normal. All was good for about 2 months or so and I'm right back where I started. The meds I have at home aren't working, I keep taking them anyway in hopes I might get a magic dose and some relief. No chance. I have a follow-up appt and we decide to try a few days of outpatient DHE. This is now December 2019. Few more drugs added to the mix, Compazine, Prednisone, and Ketamine spray as an abortive. You can probably guess what the results were. Within approximately 2 weeks, I had regressed to my new normal which is continuing to turn into a hell of its own. The only med that's doing anything is the Ketamine spray, but that's no picnic and you can only use 20 sprays per day (15 min apart, it's very short acting) and 40 total for the week. Now I have to decide when to take it. Am I in enough pain now or will it be worse later and should I wait? I decide that I should take it later in the day into the evening so I can at least get to sleep.

It's now early 2020, I'm miserable, but we decide we need a vacation and we go to London and Paris for a week. I'm armed with my Ketamine spray and hope for the best. Luckily it all worked out. I did as much as I could and we were OK with that. Just getting away from our everyday routine was worth it. When we got back, all hell broke loose in the form of Covid and I was back on the couch praying for something to break in our favor.

The Dr appointments continued as tele-med and the meds kept coming with no results. We decided to try another in-patient infusion. Same as the first time. It's now June 2020. This time I'm only in for 5 days, got some relief but it was extremely short lived. At this point I'm starting to get extremely frustrated. The Dr's are doing the best they can with what they have to work with. A few new drugs are coming out like Vypti , Reyvow and Nurtec, I tried them all. NADA!

Here's where the story starts to get interesting and maybe a little weird, depending on your viewpoint. Time to search out alternatives. Throughout the process, I've always said I'll try anything and everything because you never know what might work. 'All in' and 'All the above' were becoming my mantras. Google is now my best friend and I start seeing alternate ideas to manage the NDPH. What I found may not surprise you, what surprised me was what was going to be happening next.

I started seeing references to psychedelics, headache and pain. Not just a few here and there, but a lot. Psychedelics have been in the beginnings of a renaissance lately for treating depression, PTSD, addiction, end of life situations to treat and provide the help these people desperately need. There's a ton of research being done all over the world and even for headache disorders, especially Cluster Headaches as it's been shown that psychedelics break those cycles and give people back their lives. I have used psychedelics before for recreational purposes so I was not against going down that road to find the answers and the help I've been searching for the past 3 years.

I began this new journey into the unknown by reaching out to a friend who knew people that are familiar with psychedelics as medicine. I was introduced to a woman who is a life coach and a psychedelic integration coach, and yes, it's a real thing, thankfully!

We started working together in early December 2020, I had no idea what I was in for and I was all in regardless where this was going to lead. I was told I wouldn't take a trip for at least 9-10 weeks! Really? can't we just get to the trip and see what happens? No was the answer, there's work to be done beforehand and it involved a lot of internal work. Forgiveness, gratitude, letting go of the past, etc. Also, a big part was setting up a vision for a future I'd love, the who, what, and the where of a life I wanted for me and my family. Basically, it was getting my head on straight to prepare for what the medicine is going to offer. Looking back, it was the best thing I could have done. We all lay in bed ruminating over the past, second-guessing decisions made, etc. By learning how to forgive myself and others, to be grateful for all the lessons learned and to move forward has been a great help. It also opened me to learn how to love myself again. 'All the above' was another mantra for me. I have to say, this made a huge difference, almost immediately, in my mental health. Along with that, I started meditating regularly 2 times a day, another game changer. I also decided to stop all the meds I was on; they weren't working anyway.

This brought us to the concept of Intention, Set and Setting when doing psychedelics. In the past it was about having fun. Now it's about getting into my

head. I set my intentions on being healthy, learning how to love again and to be present for my family. I was also looking for answers for the future. Now that I have my intentions and mindset in a good place, you make sure you're in a good, relaxed, calm setting to be in for the journey. This was in the middle of covid, so home was the choice. I set up my man cave with a comfortable air mattress, an altar of sorts where you bring in personal items to help ground you. My coach put together a music playlist, mostly nonverbal music, most with an eastern meditation feel along with some of my favorite tunes mixed in.

It's now February 5th, time for my journey. My coach was also my trip sitter. She made sure I had everything I needed and most importantly, that I was safe. This is important, especially for people that have not had any experiences with the medicine. I took 2 tabs of LSD, approximately 250 micrograms. The first 2 hours or so, I was wearing eye shades and laid down on the air mattress with the music started. I was going to get into my head and I was prepared. We later went outside to watch the clouds, one of my favorite things to do while in my altered state. Went back in, talked for a while, went back into the eye shades and music and a few hours later it was basically over. My coach left knowing I was fine, I took a shower, ate something and eventually got to sleep.

For those not familiar with psychedelics and their effects, you are in an altered state of consciousness. You hear, see and feel things much differently. You're hallucinating, your perceptions of time and space are different. What you're seeing morphs, colors are brighter, the music speaks to you differently. Your mind opens up to new and different possibilities. This may seem scary not having your normal control of things. When prepared you will step into whatever is presented and know that will pass. You will come out the other side with a greater understanding of yourself.

The journey was an amazing experience, it got very emotional. Lots of crying, but all for the good. I finally got a chance to say goodbye to my dad who passed away in August. The medicine also revealed how I withdrew from everything, especially my family and that needed to be corrected ASAP. This may sound to some like a bad or difficult trip. I did not feel that was the case for me.

The amazing part was I woke up the next morning with 50% of my pain gone. It felt like a huge weight had been lifted off of me. I was in a great mood, I started journaling to get as much as I could remember down on paper. Mostly thoughts, impressions, feelings. It could have been one word or short sentences to capture as much as possible before my memories started to fade. This was a very important

step to start the integration process. This is where the psychedelic integration coach part comes in. You need to take all that was learned from the journey, what the medicine offered you and to start integrating this into your life. You can't just say that was fun and move on. You're missing the lessons taught, the feelings, the ideas that came through to you. Take the day after off, get into nature and reflect, absorb the experience. Do not get back into your daily routine. Give yourself some space. This process can be short or long, all depending on how prepared you are and the depth of what you experienced. Everyone is different.

As the days followed and I was living in my new reality of less pain. My personality and overall well-being were coming back. I was more available, I was smiling again, I was hopeful that I found something that actually works on these damn headaches. Nobody I shared my experience with could believe what has happened. They were all very happy for me, especially my wife and daughter, who I can now be a Husband and Dad to. Doesn't get better than that. Alan is back!

In the weeks to follow, I also started micro-dosing LSD, taking very small amounts that are not psychoactive, for me this was about 5 micrograms every third day for 6 weeks. Meaning you do not feel any of the psychedelic effects but get all the benefits like mood, energy, creativity, overall well-being. I'm not sure if micro-dosing was able to extend the reduction of pain, but it did help in the other ways mentioned. I finished up my 12-week course with my coach, but she's been there for me since and we're now good friends. I owe her everything!

As the weeks passed, everything was going great, pain levels were in the low numbers consistently. A few occasions of a spike here and there that didn't last too long before retreating. I was going out of the house, seeing friends, etc. It was about the 10th week after my first journey that I noticed the pain was starting to creep up where it was starting to be noticeable. I started to think that maybe it was getting time to dose again and go on another journey. Maybe the medicine has its limits?

On April 15th, I tripped again. I used all the tools I learned from my coach and made sure I followed the Intention, set and setting and that I prepared. I was actually supposed to do it the week before, but I received a phone call about my mom who was in a long-term care facility and that she was having some medical issues. I immediately rescheduled my journey as my mind set was definitely thrown out the window. Everything with my mom was resolved to where she was comfortable and out of trouble and I again was prepared for the following week.

For this I took 2 tabs of LSD, this time it was approximately 200 micrograms. I did the eye shades and music for a couple of hours, went outside, to enjoy some nature, clouds, the water. Back in for some more music, etc. I again crashed out and wanted to be in a quiet space after about 8 hours. No crying this time, nothing but smiles all day. This time I started journaling before I tried to get some sleep. Woke up the next day feeling a little tired, but the headache receded back to lower pain levels. I believe it also helps reduce how my triggers, like photo sensitivity and sound, affect my head. An added bonus to the mix. Maybe the medicine is starting to expand its role? I certainly hope so.

This brings us up to the present. It's now early July 2021 and my 10-week window is closed and starting to notice a similar uptick in the pain numbers, still very manageable. I don't want to give it too much opportunity to rear its ugly head. I took my 3rd journey this past weekend. I prepared myself the same way I had for the first 2 journeys. I want to make sure that my experiment was consistent. I took 2 tabs of LSD, approximately 200 micrograms. The dosage is based on information from my source without the ability to do a legitimate lab test. The average dose on the street I'm told is 100 micrograms per tab. I was home for the trip. My wife was my sitter. I took the medicine around 3pm, and started to get off around 3:30. At that point I went into my man cave, put on the playlist and eyeshades as I've done the previous 2 times. Everything went pretty well; I came out of the eyeshades around 6pm and decided it was time to get outside and enjoy the beautiful day. The clouds, the birds, especially the hummingbirds did not disappoint. Stayed outside the rest of the evening, my wife built a beautiful fire at dusk, we listened to music, talked, laughed, maybe a little cry here and there. It was a beautiful experience. The medicine gave me a few messages which I need to integrate and figure out how to move forward with them. I finally had enough stimulation, maybe the over stimulation is what causes the headache to change? It was time to get quiet and try to get some sleep. Not an easy thing. That was around 10:30pm and I don't think I feel asleep until 4:30am! there has to be a way to do this in a shorter time frame. Something I need to research as well. One consistent thought was I might be tripping for the rest of my life every 10 to 12 weeks in order to have the life I want and love. Maybe the more I do it, the less I'll need it? My hope is we can find a way to get the medicine into a smaller time frame. The bottom line is It worked again. This is only day 2, but I'm feeling confident that it will stick the same way journeys #1 and #2 did.

Some closing thoughts on the past 3 $\frac{1}{2}$ years. It's my belief that I've had the same headache for all this time, not a series of headaches. The LSD is a game changer, a life saver, a relationship saver. I feel I got a 2 for 1 with this medicine.

First was with my mind and spirit, I was able to get my head together, or as I told my coach, I got my head out of my ass! I'm a better person all around for it. The second was with my body. My understanding is that the LSD molecule attracts/binds to the Serotonin receptor, 5-HT_{2A}, which could help with Neuroplasticity and Neurogenesis allowing for new connections in the brain to be made. This all sounds great, and I hope I described it correctly. All I know for sure is that I was able to find a way to get this headache disorder, **New Daily Persistent Headache**, where I'm in control. Not the other way around.

I'm not suggesting anyone run out and do this. You'll need to do your own research and talk to whoever you need to, weigh all the pros and cons- remember these are illegal substances and make an informed decision for yourself. Remember: **YOU ARE YOUR OWN BEST ADVOCATE**. I am hoping that this story will help open up more awareness of alternative treatments and for research opportunities for all headache disorders, whether it's NDPH, Migraine in their many forms or Cluster Headaches. These are debilitating diseases that make people's lives miserable, not just the patient, but their families and friends as well.

I'm grateful that I found something so quickly. I read stories about how many others have been suffering for years or decades with headache disorders and struggle to find relief, my heart goes out to them. I'm fortunate and grateful that I've had amazing support from my family, friends and my doctors who I've been completely open with about these experiences. I hope this will help at least 1 person find relief. One of my life visions after my first journey was to be able to give back and tell this part of my story. Here it is. Peace

Update

Here's an update since this was written back in July, 2021

I continued to try and find the best combination of dose and frequency. The only conclusion I have is that it didn't matter whether the dose was a high dose or an average/recreational dose, I always ended back to the same baseline. I look at that as a win. I'm not going backwards! The frequency seems to be 1x per month as maintenance and feel like 100-150 micrograms of LSD or 1.5- 2 grams of Psilocybin seem to work fine me. I haven't found microdosing helpful for pain, but have found it helpful for my psychological well-being.

My advocacy started getting into full swing in September when I was asked to be the patient advocate for NDPH for the Association Migraine Disorders Symposium. I recorded this journey and it was available for the community to see.

Next I volunteered virtually for the Retreat Migraine and the Clusterbusters conferences. Starting in January, I volunteered to be a Community Support Ambassador for the Migraine World Summit, the largest online Migraine conference held in March. That brought me to Headache on the Hill. I was part of the Maryland team that had virtual meetings with staff members of Senators and Congress members for my state. This was exciting as we had the opportunity to affect policy coming from Washington to help the Headache community. This years asks were for the American Indian/ Alaskan Native population to get better access for the headache disease treatment and we also asked to have a review on how the NIH assigns funding for research. The NIH has agreed in the past to look at disease burden on the population as a factor in their decision for funding. Headache is woefully underfunded based on it's impact. We receive around 8% of what other diseases with similar impact get. We need this corrected and get NIH to do what they said they'd do! All these experiences have been more rewarding and motivating that I could have imagined and will be continuing on this path for as long as it takes to get answers.

It's been almost a year since I reached out to find someone to tell my story to and get this out there. I'm please to say that through the help and support of Clusterbusters, Inc. This website you're on, NDPHaware.org, is now a reality. The focus is to get research, educate people and to advocate for NDPH. I hope you'll join me.