

Timeline of operations, procedures, and medications 2006-2023

On page 18 to 23 are my FINAL THOUGHTS

2006-2009

- During the onset of pudendal neuralgia (PN) in 2006, after an injury to the right-side pudendal nerve, Amitriptyline and Clonazepam were prescribed. **Amitriptyline was prescribed to derail pudendal nerve pain signals to include; chronic, satanic acid like burning and electric shocks and worked well. For sleep problems caused by PN symptoms, .5 mg of clonazepam was also prescribed.** Continuing those medications for the next four years enabled me to work and sleep, but changed who I was.
- Amitriptyline was originally developed as an antidepressant before doctors found it also helped relieve pain. Being prescribed a drug developed for depression when I was very happy and not depressed, caused secondary side effects such as insomnia.
- “The Ashton Manual (revised 2002), BENZODIAZEPINES: HOW THEY WORK AND HOW TO WITHDRAW CHAPTER II: SLOW WITHDRAWAL SCHEDULES Schedule 5” reports, **“(0.5 mg clonazepam is approximately equivalent to 10 mg diazepam).”**¹ In 2006 this daily dose of benzodiazepine equivalent to 10 mg of Valium, along with 60 mg amitriptyline a day, stopped the physical symptoms. Ultimately however, this created huge cognitive changes in my personality and how I perceived and processed decisions.

(The dose in the first few years was 30 clonazepam every month at .5 mg per day, and was increased by 2013 to 120 pills for a 30-day supply. This is the equivalence of 40 mg of Valium a day.)

2010-2012

- In 2010 after four years on clonazepam and amitriptyline, in early January dystonic symptoms gradually appeared causing my shoulders to shrug inadvertently, and my hands to fly off the key board of the computer.
- From January to February the flinching and ticks became gradually worse.

- In February numerous narcotics were prescribed for pain during and after knee replacement surgery.
- By March three months after the first dystonic symptom the ticks and jerks had morphed into full-blown unabating dystonia.
- The ER doctor named **Amitriptyline as the catalyst** for the dystonia and **I was instructed to slowly titrate off the medication. A second movement disorder specialist came to the same conclusion, stating that the slow onset of symptoms pointed to medically induced dystonia caused by the amitriptyline.** However, the dystonia may have been exacerbated by the addition of multiple pain killers prescribed after knee replacement surgery. Every muscle in my body to include my face would forcefully jerk and twitch, with less than a second between terrifying movements. Diazepine was then prescribed to help calm the dystonia.
- The physician did not have me titrate off Clonazepam and immediately switched my prescription to the generic form of Valium called diazepam to manage the ticks of dystonia. **Consequently, I was simultaneously withdrawing from clonazepam (equivalent to 10 mg of Valium) and amitriptyline, while consuming a 5 mg daily dose of diazepam. As a result, within two weeks I felt the same feeling of impending death which Dr. Huff described in her open letter detailing her benzodiazepine journey. A feeling of impending death, coupled with the side effects, which Dr. Heather Ashton described as “emotional blunting” and “emotional anesthesia”, made me feel disconnected from everyone, and belongings no longer held sentimental value.**

I threw out artwork I had created, treasured letters and photos saved for over 30 years, and anything I did not think anyone would want when I was dead as the feeling of “impending death” from the clonazepam and amitriptyline withdrawal, and side effects of diazepam, increased daily. Becoming more detached from reality and physically impaired, I forged on like a functioning alcoholic, which continued to be the hallmark of many years to come.

- **Muscle weakness, nausea, and slurred speech were experienced in the first month. By the second month the muscle weakness had resulted in the inability to walk forcing me to crawl from room to room. Unable to speak (because the tongue is a muscle), my voice was distorted and unrecognizable. I started losing hair and my thinking was extremely warped. Due to the extreme nausea, towels were placed under the doors to block cooking smells from entering my room. At five foot seven, I eventually weighed 103 lbs.**
- **Without amitriptyline to block the pudendal nerve pain all PN symptoms returned to include, endless acid like burning and electric static. I wanted to die to escape it but fought on.**

- **Two weeks before the first pudendal nerve block (PNB)**, returning to my neurologist I inquired as to my extreme weakened state. He prescribed more diazepam and while there joked that I needed a prescription to Haagen-Dazs ice cream because I was too thin. I was losing weight due to prescription induced extreme nausea, and would arrive at every doctor appointment dragging my feet while struggling to hold up my head. Unable to enunciate it sounded like I was growling as my words were drawn out in extreme slow motion. Every sentence was one endless connected word. My legs felt like Jell-O and I was deteriorating rapidly. None of my doctors could diagnose what was wrong with me.
- **During this time, I had my first pudendal nerve block (PNB).** When the OB/GYN who ordered the PNB was **asked if there were any possible side effects he answered, “No we do these all the time.”** Yet in the medical records, he states that the risks were covered. The day of the PNB the nurse prepping the me responded to the same question with, **“No we do these all the time; you may get an infection at the site of the injection.”** Then answered, **“Yes”** to the question **“Will antibiotics clear that up?”**
- While being prepped for the PNB, lying on the table physically exhausted and mentally anesthetized from diazepam; I levitated twice in rapid succession (possibly dystonia), remembering the sound it made as I slammed onto the metal table. The nurse, J.C. McMillan informed the person who came with me to the appointment that she had never seen anything like it in all the years she had been a nurse.
- **The first pudendal nerve block with Depo- Medrol caused new co-morbid symptoms to include, persistent genital arousal disorder (PGAD) and additional neuropathies in the anus.** Suffering severe debilitating drug side effects and rapidly losing weight the PGAD symptoms came and went. I thought it was all part of the medications as one hour blurred into the next. I also had just tried OTC testosterone and mistakenly thought that too could have been the cause.
- **Two weeks after the first PNB barely able to walk**, returning to my general practitioner I asked if the Valium was making me weak and sick. His response was, **“It can’t be the Valium, you are only on 5 mg.”** He kept me on Valium and wrote under his treatment-plan, **“Valium 5 MG TABS, once a day, 30 days, 0 refills.”**

I could barely keep my head up and with slurred speech, and on the edge of death, I would point to myself and tell those I spoke with, *“I am in here.”* Numerous blood tests were run and later during one visit he wrote in his office notes that I had slurred speech, **“neuro: speech sl dystonic with some abnormal facial MVT’s, takes valium 5 mg hs.”** Yet, he did not take me off the diazepam. This kind of confusion when diagnosing a patient on benzodiazepines is covered in, *“How Benzodiazepines Mimic Chronic Illness and What To Do About It.”* (2018) by Janice Curle, **“With continuing use, sometimes within weeks, sometimes taking years, the patient’s health may begin to decline, often with seemingly no explanation....Some patients consult numerous specialists in this time, chasing their tails in search of answers to their mysterious ills, and still do not receive a proper diagnosis.**

After numerous tests and sometimes the passing of many years, a few lucky patients discover, usually on their own, that the long-term benzodiazepines prescription was responsible for their problems all along.”²

- Approximately three months after starting diazepam I came off per instruction of a neurosurgeon. I asked him a slurred one-word question, “*whasswrongwithme?*” Upon review my symptoms had checked all the severe side-effect boxes for diazepam. Unadvised to slowly titrate off the diazepam, as 5 mg was considered at the time a low dose, **and too drugged to know better, I stopped cold turkey and a third withdraw ensued. A slow taper off any benzodiazepine at any dose taken for any amount of time is crucial.** University of Texas Medical School’s Dr. Charles Bernhart wrote in 2018, “How to deal with benzo withdrawal (Xanax, Klonopin, (Clonazepam) Atavan, Valium, etc)?” He offers an extreme tapering suggestion indicative of how gradual these tapers often need to go. “*Here’s a trick I sometimes suggest to my patients: when your dose is pretty low, gently drag your pill across an emery board before you take it.*”³
- **Shortly after the rapid withdrawal from diazepam** taken to calm dystonia, **all dystonic (extrapyramidal) symptoms returned.** Warp speed, horizontal vibrating across my entire face under the skin appeared for a few seconds and then left never to return. The surreal horror of it alone will stay with me for life. **Now living with family because of my weakened state I continued to suffer unfathomable dystonia, sleep deprivation, acid like burning, and staggering withdrawal symptoms. In a constant state of fight or flight, it felt like my brain was on fire. While there I had a second PNB.** While on the table being prepped, my radiologist’s nurse said I spoke as if I were, “*from the islands.*” Tongue and throat muscles can be weakened, making speech hard to understand. My slurred speech had turned to an ‘accent’ of sorts as the diazepam began to wear off. This enabled me to slowly start to use my tongue again. On “*MayoClinic.org*” (2018), it points to this as possibly being dysarthria, a manifestation described as slurred or slowed speech caused from medication.⁴

On the University of Dallas web site under, “*Foreign Accent Syndrome*” was a section allowing one to hear patients with apraxia. It is no longer there however, I embedded the MP4S in the original research paper I wrote so they can still be listened too. But because this is a PDF post they have been removed. I did not have apraxia. However, while titrating off diazepam my voice mirrored the patients on the site. This has enabled me to share with others the phase of my speech which the nurse described as “*an Island accent.*”⁵

However, if you google “*audible sounds of a patient with apraxia*” or a video you may find what it sounds like to not be able to use your tongue, like I endured on valium. If you hold your tongue to the bottom of your mouth behind your teeth and do not use it to speak, you may also hear an accent of sorts like I experienced.

- **After the second PNB** with Depo Medrol, still crashing from diazepam while experiencing protracted withdrawal symptoms from the discontinuance of amitriptyline and clonazepam, I woke to horrifying clitoral arousal, crushing restless leg syndrome, and a myriad of foreign body symptoms. **Unable to walk or think I was driven to the last PNB appointment by a family member, where the radiologist told the two of us that his PNB had caused the PGAD I was experiencing. He explained that I had a 1% chance of getting PGAD. Saying, he had performed three hundred PNB, and three patients had gotten PGAD and I was the third. He said in time it would hopefully disappear, but never did.** A family member who witnessed the conversation then documented it. It was notarized due to the importance of that moment, and the need for collaboration when discussing the illness with doctors in the future.
- I was exhausted and as my hair started to fall out. I became nearly suicidal from the **relentless arousal, extreme weight loss, residual effects of dystonia, acid like burning, foreign body symptoms, and sleep deprivation. Irrational due to pharmaceutical cognitive dysfunction from the extended withdraw from amitriptyline and clonazepam, and the sudden withdrawal from diazepam,** I would make unimaginable calls to the radiologist who caused the PGAD.
- Withdrawing, crashing and medicated, these heart-breaking messages were left on the doctor's voice mail in tears, begging him to stop the relentless, morbid PGAD symptoms his PNB had caused. I was fighting for my life and in retrospect, I do not know how I survived those months which turned into years, and the embarrassment of things said and done on benzodiazepines and during an ongoing protracted withdrawal. The memory of it all remains horrifyingly palpable. These medically induced, warped, tear saturated calls were also made to friends and family, begging desperately for them to find a way to stop the all-consuming PGAD symptoms and the **terrifying abyss the withdrawal had produced.**
- **No one to include myself realized the extreme behavioral changes were linked to the medications.** The memories of these pharmaceutically fueled conversations, along with calls made during several multiyear protracted withdrawals are disturbing.
- Living with family now weighing 103 lbs. at 5'7, I forced myself to eat three Hungry Man TV dinners a day with shakes of chocolate Ensure and ice cream with each meal in a futile attempt to gain weight. In a constant state of fight or flight I rapidly burned off every calory consumed.
- A vegetarian all my life, suddenly the thought of vegetables now made me nauseous as a result of the altered neuro transmitters, serotonin, dopamine, and GABA. **Hanging on by a thread, over a month after stopping diazepam cold turkey, four months after stopping clonazepam cold turkey, and while taking Tegretol; I asked to be taken to the emergency room (ER).**

I told no one, but continued to want desperately to die. I was afraid if I said I wanted to die, the doctors would not understand it was the medications, sleep deprivation and PGAD which were the culprits of the desire. As prior to this nightmare I was extremely happy and healthy.

- **While staying with family and after a month without sleep I had a family member take me to the ER room. The ER doctor was a lifeline. While there I was given oxycodone for sleep while being observed to see if there were any negative reactions, given my history of drug sensitivity. It was an ER room full on a busy memorial weekend, in a city with one of the highest murder rates. Yet she held my hand, squatted by my bed to be face to face with me when she spoke, believed me, and listened. Her attention made me feel valued at the time when I was hanging on by a thread. Sleeping after over a month with none due to PGAD and withdraw allowed me to continue to fight for my life. I knew I would never forget her as I felt she had saved my life.**

I left with a prescription for oxycodone unknowingly accelerating my downward spiral. I was desperate for relief and no rational thoughts were given to anything I said, or medication I consumed. All I knew was the oxycodone enabled me to finally rest after about thirty-eight days without sleep.

- A month later in October still desperate to escape PGAD symptoms, I asked my OB/GYN NP to arrange admittance to the hospital which she was affiliated. (The Oxycodone enabled me to get sleep, but did not negate the PGAD symptoms.)

The goal was to try pain medications where I did not have to travel for hours back and forth to my home with PGAD for every bad drug reaction I might encounter. However, now in an **accelerated pharmaceutical state of decline because of the oxycodone**, I was convinced the same severe reactions I had recently experienced with almost every drug previously prescribed would be mirrored in any newly prescribed medications. Hence, **the doctors were speaking to someone with only a pharmaceutical link to reality, as I refused to try the medications offered me.**

While there a doctor (Dr. C) came in my room who I believe was a geriatrician, she suggested my PGAD was due to unresolved rape issues from thirty years prior. I felt like a lab rat as she observed me, suffering from unrelenting diaphoresis, PGAD while withdrawing, with what I perceived as a lack of empathy. I handed her a name of a specialist within the same hospital and asked her to contact them. She refused saying, "We only ask them for help in emergencies."

Withdrawing is terrifying. It's like balancing on the edge of a cliff, looking through prescription glasses ten times more powerful than you need. **I am sure the doctors were unaware and frustrated. I left the hospital with two new prescriptions (15 Dilaudid, a narcotic and 40 Temazepam, a benzodiazepine) in a pharmaceutical free-fall.**

- By November on the aforementioned medications along with Oxycodone prescribed in the September ER visit, I met a new PN surgeon in New Hampshire. I presented as moderately aware. However, I was in a state of pharmaceutical dysfunction. For the flight to see him I had been escorted by a friend who flew with me, wheeling me to and from the plane in a wheel chair as I felt like a rag doll and could no longer navigate life for myself.
- I had ingested two .5 mg of clonazepam equaling 20 mg of Valium for the flight to keep flairs at bay. They were left over from the previous sudden switch to diazepam. I am sure any choices made or answers given while there were unintentionally incorrect. Choice, involves judging the merits of multiple options. I was on prescription fueled autopilot, my decision-making had been hijacked and all actions lacked cognitive presence.
- I moved into a hotel in NH for the next five months so I could see the specialist and the pain management doctor which he worked with at the time. **Prior to pudendal nerve decompression surgery, between the PN specialist and the pain management doctor, multiple medications, a Tens Unit, an epidural, psychiatric assessment, a multiple day ketamine drip, seventeen pudendal nerve blocks (PNB) with lidocaine, bupivacaine, and heparin, were tried along with several bilateral dorsal clitoral nerve blocks and sacral epidural local anesthetic injections.** Nothing seemed to work long term and the tricyclic antidepressant prescribed to derail the PGAD symptoms caused more dystonia as it was from the same class of drugs as the Amitriptyline that originally caused dystonia. As for the seventeen PNB given near the sacral plexus, it is my belief that they caused permanent arousal in the sacral plexus. Instead of calming the nerve had the opposite effect, aggravating the nerve and eventually causing permanent problems, possibly caused by the detergents in the anesthetics, in addition to the following theory inspired by Dr. Quinn H. Hogan research on topical anesthesia. Possible Mechanism of Irreversible Nerve Injury Caused by Local Anesthetics "Detergent Properties of Local Anesthetics and Membrane Disruption" Norihito Kitagawa, M.D. Mayuko Oda, M.D. et al (Nov. 15, 2003) states, that attention concerning the link between the two increased following the description in Rigler et al¹ connecting cauda equina syndrome and continuous spinal anesthesia with 5% lidocaine, as irreversible nerve damage can be caused by detergent properties of local anesthetics.

The following quote found in Pathophysiology of Peripheral Nerve Injury During Regional Anesthesia (2008) by [Quinn H. Hogan](#), M.D. addresses topical application of anesthesia. *"Topical application of local anesthetics decreases blood flow in nerves,^{11,12} which may either cause injury directly by ischemia or potentiate direct cytotoxic effects. As with other toxic effects, local anesthetic vasoconstriction is related to the concentration of the drug.¹³ The mechanisms of these vascular changes may be inhibition of endothelial processes regulating nerve vessel tone.¹⁴"*⁶

This may support the theory that a high dose of a topical anesthetics like 20% compounded lidocaine systemically absorbed, could aggravate a sensitive area such as the clitoris of a PGAD patient causing arousal after the lidocaine has worn off. In 2021 I experienced this phenomenon after applying 20% compounded lidocaine topically on the clitoral area nightly, over the course of five days. Each morning after the abatement of the numbing effects of the medication the patient claimed that her PGAD symptoms were worse, when 10% compounded lidocaine in the past did not have the same effect.

- From 2-15th in November of 2010 I stayed in a New Hampshire hospital enduring multiple medications, three days of intravenous ketamine and various other attempts at stopping PGAD symptoms. The Ketamine treatment was a nightmare, as I stopped breathing at one point, tethered to the ketamine drip and thought I was dying. The following account was lifted from a post I made about the experience on the Pudendal Hope forum.

“A female doctor came bedside to introduce herself adding, “You will not remember anything I am saying but you will be fine. I have done this many times before.” However, I remember most of it to include, lying in bed paralyzed, with my eyes open, unable to move or breathe, and yet aware of everything. The situation was relayed with urgency, by a nurse over the phone to her support, while she continually pleaded with me to speak. The nurse on the phone asked me one last time to speak. Finally, able to respond slowly I asked, “Am I dying?”

She responded, “No, you’re not dying.” This was immediately followed by a relieved, “She’s talking!”, which were the next words she delivered to the person on the phone. I had nightmares and hallucinations on Ketamine, and experienced a “co-dependent’ side effect, which made me terrified to be alone. I was on a drip for three days, however a week later after being discharged and returning to the hotel, I still felt the effects of Ketamine. I would shut my eyes and see colorful flashing lights, and start to feel the effects of the medication. Afraid it was permanent, I called my doctor who said he was surprised I was still experiencing these side effects, and in a few days, it lifted.”

- I was readmitted to the NH hospital from March 18-29, 2011, where I had a caudal epidural and on the 23rd pudendal nerve decompression (PND) surgery and clitoral branch neurectomy.
- After a total of five months of living close to my team of doctors, I moved home. I was terrified to be where no one understood the illness. I took my medications and waited for my body to heal, with the understanding it could take three years. Because of the plethora of prescriptions, I was drugged into sleep for many years. When awake I suffered all the original PGAD symptoms only slightly muffled, along with a few new foreign body symptoms. The worst foreign body symptom was the feeling of a broom stick being inserted in to my anus along with a feeling of sexual arousal. It was pure hell and I just existed, constantly wanting to give up.

My days were spent in a labyrinth accidentally bumping into things I had to do. I disappeared from family and friends. Every part of me had been hijacked by the medications. From what I ate to what I wore or said, was turned on its head. Then in 2011, I joined Pudendalhope.org which I found online while searching my disorder. There I found other women like myself for the first time. This brought the diagnosis a sense of credibility I had not previously felt.

2013

- **In March of 2013 my clonazepam prescription was increased to 120 five mg tablets of clozapine a month, the equivalence of 40 mg of Valium a day.** Three times what I had been on for eight years. There is a direct correlation between the increase in clonazepam and the poor decision to have a redo surgery of the pudendal nerve in 2013, only two years after the initial surgery in 2011.

PN specialists usually suggest waiting at least three years after your first surgery to have additional pudendal nerve surgeries. I had attempted to titrate down 5 mg. from the 10 mg. daily dose of Lexapro I had been on and all my symptoms returned, triggering my decision.

After which, I waited too long to return to the initial 10 mg dose and when I did days later, my body had built up a fire wall and the 10 mg no longer worked and had to be increased by my Dr. to 20 mg. which has been, and is to this day in 2023, taken with 75mg Lyrica three times a day. I was not warned of this phenomenon from any medical professional prescribing my medications.

However, in 2013 I learned of this from my second PND surgeon after it was too late. Void of any cognitive processing, desperate for relief and poly medicated, I traveled across the country to Arizona to have right side re-do surgery performed by a well-regarded PN specialist in May.

- A small amount of Clonazepam was kept on hand for severe pain for several years after the final benzodiazepine titration in November 2013. Very few were taken each year in the beginning, to none as the years went on. Eventually oxycodone was also discontinued, as it was causing truncal-like dystonia and other dystonic reactions.

2014

- The original horrifying PGAD/PN symptoms experienced after the second PNB are now down to approximately fourteen. Any one of which alone would devastate any woman.
- In 2014 a year after titrating off clonazepam, still experiencing a protracted withdrawal, I would ramble in endless conversations, emails, and texts. I was still unable to complete a small to-do list, make it to appointments on time or the right day, and often would navigate the wrong month forgetting to turn the calendar to the correct month.
- I fought to follow a to-do list by placing only one to-do item on one sheet of paper, and placing them on the counter. The goal was to pick one sheet up and do the task, leaving an empty space on the counter indicating that something had been completed to invoke a sense of accomplishment. It only worked for a day or two, and then the papers on the counter bled into the background and went unnoticed. The to-do items were simple things like vacuum, stand outside for fresh air, or call your mother. They were basics that everyone takes for granted. I had to keep tricking my brain to do things. Determined, I went back and drew a cartoon on a sheet of paper and colored it with neon highlighters, and with my copier made a stack of copies. I wrote one to-do item on each sheet and laid them back on the counter as I had done before. However, this time it worked as my brain was attracted to the neon colors in the sketch and I would pick them up which was half the battle. Before getting sick I was athletic, competitive and an artist. I attribute all these traits to the tenacity it takes to survive all aspects of my PN/PGAD journey.

2015

- Five years after the onset of PGAD in 2010, and nine years after the onset of PN in 2006; PGAD and PN symptoms were waxing and waning. New symptoms are coming forward, because of the discontinuance of clonazepam. Now, possibly one less symptom than a year ago, the main symptoms remain while the others move and change location and intensity.
- Continuing to make poor decisions while experiencing a multi-year protracted withdrawal; I opted to have an avoidable non-PN related fractured femur **surgery. Uncharacteristically, I made this decision without obtaining a second opinion. As, during protracted withdrawals I could never think anything through. I could only do the first half of things. Anxious to do surgery the doctor had me convinced that even using the clutch in my car for the drive home from the initial appointment could cause the femur to crack more.** However, after surgery I was told by several doctors who looked at my x-rays that with bed rest the femur would have healed itself.

The avoidable surgery of a fracture to the femur resulted in two major surgeries. The first, to place a huge rod in the hip and femur, and a second surgery a year later by a trauma surgeon to have it removed. As it was done incorrectly the first time. Again, this demonstrates the domino effect of the PN journey.

- Prior to this PN journey I was an extreme minimalist who loved living alone, coming and going as I pleased. However, these traits disappeared under the influence of medication and have not fully returned. Pharmaceutically eviscerated I became claustrophobic, codependent, terrified of being forgotten, or of living alone. These indications are labeled “emotional dependency symptoms”, which Dr. Ashton covers in her manual on benzodiazepines.
- In the early years before titrating off benzodiazepines, as I was sent photos of friends and family, I would print them out. They were taped in a collage covering the span of four folding doors in the kitchen. I felt like I would suffocate without their faces. It was uncharacteristically strange for me to be so needy, or tape pictures or anything on the walls as I hated clutter.
- Proof that it was drug-related came much later during a protracted withdrawal from clonazepam. I remember walking into the kitchen and seeing the cluttered wall of photos as if for the first time, as if I had walked into someone else's home. I thought they looked like a child had taped them to the doors, and they were immediately taken down.
- In that moment it was like finally touching down after fighting a turbulent landing. Documenting many cringe worthy epiphanies such as this during my multi-year protracted withdrawals were a relief, as each one indicated my brain was healing.

2016-2018

- It’s hard to keep track of symptoms while trying to survive, but it seems the remaining symptoms are again the worst and most persistent. The PGAD symptoms in the sacral plexus where the pudendal nerve is attached, clitoris and right labia minora are by far the worse three areas. Over time horrifying allodynia and central sensitization has increased, and crawls over my back daily and must be covered in Salon Pas Hot Gel patches and or ice. **As for the extended withdraw these are a few of examples of cognitive issues during 2016 to 2018**
 - ...bread would go in the toaster, items in the microwave and the second step of popping down or turning on was never done
 - ...out of the five steps for making coffee (adding coffee to filter, adding water, shutting lid, plug in, and turn on) I would leave one or more steps out
 - ...occasionally when I prompt my Bluetooth to make a call, between requesting the prompt and hearing the response prompt, my attention will drift requiring multiple tries before the sound triggers my brain to request a contact

- ... occasionally I struggle with how to use my phone and the TV remote
- ...opened 4 drawers to find an item, and often find things in the wrong drawer
- ...occasionally I stop in the middle of a sentence and have no idea what I am talking about
- ...forget the names of common objects
- ...I was unable to say the word “animal”, however I knew the word I wanted to say, I just could not say it. I would say aloud, “annual, anvil, etc...” However, it would not come out as “animal.” It was upsetting to hear myself struggle with a simple word that I could see in my mind, but not say
- ... picked up the cell phone to call pharmacy about a prescription and typed in the contact bar the word “drugs”, and could not figure out why it did not work
- ...complex tasks must be done several times to be completed successfully
- ...continue to sometimes get confused on how to use phone and TV remote
- ... sent an envelope to my friend Dr. Millus in the UK and addressed it to Dr. Samuel, which is her son’s first name
- ...tried to type the word “with” and did not recognize it and had to use spell check.
- ...can go into a room four times to get something done, forget why I am in the room and will start four more projects
- ...continue to have a short attention span, when talking to someone I sometimes find myself looking to either side of them or beyond them and do not make eye contact
- ...saw my sister-in-law’s name on the calendar and could not remember who she was
- ...while typing, got confused on the difference between W and Y
- ...filled in my address online and could not remember the house number. I struggled for 5 minutes until it finally came to me. When I go completely blank on anything, I can never just let it go. I will do everything in my power to recall what is forgotten, no matter how long it takes

- ...I can best describe my brain as feeling like it is made of Teflon, where nothing sticks

2019-2023

Symptoms and medications have remained the same, 20mg of Lexapro for nerve pain and 75mg of Lyrica three times a day, with no procedures or operations on the horizon.

- PGAD symptoms sadly remain the same. However, the strange “touching and pressure” feeling down the right femoral nerve is more prevalent and must have hot gel patches and a four-inch bandage to wrap it in, to apply pressure which seems to help a lot. That along with allodynia, and central sensitization are the main physical complaints.
- **Due to GABA damage from benzodiazepines, patients on forums have reported changes in voice modulation, sleep patterns, memory, emotions, cognitive processing time,** along with **extreme startled reactions to normal stimuli** (like a phone ringing or a knock on the door).

I can go from conversing normally then within the confines of a conversation if I get unexpectedly slightly anxious or emotional, whether happy or sad, my **voice unnaturally instantly elevates without warning as if experiencing terror and is unrecognizable to me.** These uncontrollable changes in vocal modulation and syncopation during my daily communications are embarrassing, representing the death of my ability to present my thoughts eloquently. Once articulate, now aware of these new behavioral changes I am guarded as to whom I have extended conversations. In addition, I now experience cognitive and emotional fluidity, and emotional dependency. As a result, **I can no longer live alone, something I use to embrace. I use to be very social which meant the quiet few hours home alone to create art or write, became the time in which I seemed to recharge. I now stay where expectations equal my talents and where I am not asked, “Where do you work?” as I no longer can, or where I am told, “You don’t look disabled” as invisible illnesses cannot be seen.** There is a trail of uncharacteristically embarrassing things said and done while medicated and withdrawing, which I am well enough now to see as mortifying.

- No longer as poly medicated as I was in the past on benzodiazepines, sobbing and traumatized calls have ceased. I still suffer from the effects from Lyrica and Lexapro, which I still take, PN, PGAD, and damage to the GABA and my central nervous system.

The calming neurotransmitter GABA's function was preformed chemically for so many years by benzodiazepines, that it is now damaged causing severe insomnia, and many other problems already discussed.

Sleep arrives at four AM when my body and brain are exhausted. However once asleep I stay asleep for ten plus hours to function the way I use to on eight hours or less. Setting an alarm is counterproductive, as not waking naturally invites PGAD and a foggy brain, and so like many in my shoes I listen to my body and wake when my body dictates. Sleep is the only time I can escape my symptoms.

- The end of the fifth year (2019) off clonazepam represented a definitive point of marked improvement in cognitive recovery, with ongoing improvements as the years' progressed. However, cognitive improvement is a doubled edged sword. **With mental clarity comes a detailed realization of one's losses both in personal life experiences, and in cognitive function. I now can clearly recall frame by frame every conversation, person, and every day from the past lost decade, as these memories slowly seep uninvited into my healing brain. In addition, sadly now the curtain has been forever pulled back revealing the incurable permanence of my illnesses, and the continued isolated future which is in store.** When the COVID-19 virus came and forced the world to wear masks in 2020, and social distance, for the first time in ten years, I felt like I was part of the world again. I did not feel as if I was missing out on gathering with family and friends, working, or traveling, as everyone was in the same horrible situation. Hearing the world say, they missed their old life mirrored my decade long cries exactly. After all, not seeing friends and family and being hugged because of my isolation, multiple neuropathies, and damage to my brain from medications, had become the hallmark of the last decade spent alone. Once again, a sad example of the "Domino Effect of Pudendal Neuropathy."

Time line of PN/PGAD symptoms 2006-2023

2006 – 2010

TWO PN SYMPTOMS ONLY

Pudendal Neuralgia (PN) symptoms caused by a physical injury to the Pudendal nerve:

1. Never ending static fizzing feelings in the entire vagina and mons pubis area
2. Never ending acid-like feeling on vagina

These two chronic symptoms were treated with Amitriptyline which masked the static and burning for four years, enabling me to work full time. Clonazepam was prescribed for sleep difficulties cause by PN symptoms, and sleep difficulties cause by the Amitriptyline that was used off label for pain signals, causing “hyperactivity”.

Eventually, dystonia was caused by the Amitriptyline for PN signals. I slowly titrated off the medication. Valium was prescribed for the ticks and the clonazepam was stopped without titrating. Now coming off two medications with the introduction of valium I became unable to eat or walk. Without the Amitriptyline, the burning returned. To treat the burning, two pudendal blocks were given with Depo Medrol used off label, a month apart.

These blocks caused persistent genital arousal disorder (PGAD), and other comorbid symptoms, such as (RLS) restless leg syndrome etc. It is believed the PN was furthered damaged by the Depo Medrol which formed crystals near the nerve.

After the 20 symptoms below did not pass, in 2011 bilateral pudendal nerve surgery, and a clitoral neurectomy were performed, followed by a right-side redo pudendal nerve decompression surgery. However, the majority of symptoms remained.

2010 – 2013

TWENTY-TWO PGAD/PN SYMPTOMS AFTER PNB

1. Clitoris on verge of orgasm constant
2. Bilateral Labia majora feels engorged, size of baseballs, called foreign body symptoms, (FBS)
3. Feeling of a bottle brush slowly turning in vagina
4. Raw inside vagina
5. Many bees stinging in uterus
6. A single bee stinger in center of clitoris
7. Anal prodding like a broom stick (FBS), making it unable to walk
8. Constant feeling of something inserted half in half out of vagina (like a tampon)
9. Sexual feelings in the anus and on the gluteus muscles
10. Acid burning on vagina
11. Static and fizzing on mons pubis and all areas below the mons pubis
12. Itch in vagina and anus
13. Arousal on ligament between rt labia minora and majora
14. Restless leg syndrome (RLS) (which I never had prior to the pudendal nerve block)

15. S 2,3,4 is where the pudendal nerve is attached and oversees urination, defecation, and sexual function. Because of this, there are new urination, sphincter, and gastral intestinal issues
16. Sexual feelings in lower stomach (ilioinguinal nerve)
17. Sexual feelings on genitofemoral nerve
18. Sexual feelings on femoral nerve (mostly right leg can be bilateral from central sensitization (CS) and nerve cross talk messages, sent from the L2)
- 19. Deep arousal between the entrance of vagina and the anus (which is the only symptom that left instantly after the first surgery and never returned)**
20. Arousal on the sacral plexus which I believed was caused by, or exasperated by 17 pudendal nerve blocks in that area with lidocaine (lidocaine systemically absorbed, can aggravate or damage nerves as they can contain detergent)
21. Feels like right labia minoria is being pinched. And after one of the 17 pudendal nerve blocks by a substitute Dr. (who used the wrong needle size after my doctor left him instructions telling him what to use, and who I reminded before the procedure to use the smaller needle), use the needle that was laid out. He even commented on knowing it was not the size indicated but because it was there already, he was going to use it. It was so painful that I screamed so loud the entire wing heard me. Tears streamed onto the table. Because of that block I endured a painful paresthesia in the labia majora. I cannot remember which side however; I do remember it lasted quite a while.
22. Right side entrance to the vagina, insatiable seething sexual arousal with deep pain

2014

FIFTEEN PGAD/PN SYMPTOMS

1. Insatiable itching in vagina
2. Constant feeling of large air pockets and itching on bottom of both feet (lasted for a year, appearing six weeks after the 2013 pudendal nerve decompression surgery)
3. Anal prodding
4. Sexual feelings in the anus
5. Right side wall of the entrance to the vagina feels like a sexual toothache
6. Arousal deep between the rt side labia majora and labia minora
7. Clitoral arousal less but a thought away with horrifying flairs
8. Not as much burning in vagina, except after sitting
9. Constant rt side labia minora arousal, symptom can change to a feeling of pain that feels like a vice grip

10. Sexual feelings in lower stomach (ilioinguinal nerve) can crawl up to ribs
11. Sexual feelings on genitofemoral nerve
12. Sexual feelings and deep pressure on femoral nerve (mostly right leg can be bi-lateral, from CS and nerve cross talk messages sent from the L2)
13. Arousal and pain in sacral plexus area where seventeen pudendal nerve blocks were given in 2010-2011 damaging the area, as research states that anesthesia can damage nerves. Can change to a deep painful drilling on the left side of the SP
14. Clitoral arousal less but a thought away 24-7, causing lack of concentration and hyperactivity (cat on hot tin roof syndrome) ...with continual horrifying flairs with no warning
15. Right side wall of the entrance to the vagina feels like a sexual toothache

2015-2023

TEN PGAD/PN SYMPTOMS

1. Right side wall of the entrance to the vagina feels like a sexual toothache
2. Arousal deep between the rt side labia majora and labia minora
3. Not as much burning in vagina, except after sitting
4. Constant rt side labia minora arousal, symptom can change to a feeling of pain that feels like a vice grip
5. Sexual feelings in lower stomach (ilioinguinal nerve) can crawl up to ribs,
6. Sexual feelings on genitofemoral nerve
7. Sexual feelings and deep pressure on femoral nerve (mostly right leg can be bi-lateral, from CS and nerve cross talk messages sent from the L2)
8. **Arousal and pain in the sacral plexus area. Seventeen pudendal nerve blocks were given in 2010-2011 damaging the area. Research states that anesthesia absorbed systemically can damage nerves. The arousal can change to a deep painful drilling on the left side of the SP.**
9. **Clitoral arousal less but a thought away 24-7, causing lack of concentration and hyperactivity (cat on hot tin roof syndrome) ...with continual horrifying flairs with no warning. Clitoral nerve cut as part of PN surgery in 2010 and on antidepressants taken for pain, both of which deter orgasm, make having an orgasm to reduce arousal, impossible.**

10. **At the very tip of the left pelvic bone near the Pubic symphysis it can feel as if it is being injected with arousal. If touched the nerve sends violent jerks as if you are touching an exposed nerve. Then the arousal travels into the left labia majora and to the genitofemoral, ilioinguinal and iliohypogastric nerve and up the right side of the front of my stomach, up over the rib cage to under the left breast. As the nerve cross talk crawls over my body at any juncture you can roll the skin between your fingers and feel this same exposed nerve jerking. Its sexual in nature, but not an orgasm and physically and emotionally traumatic. Afterwards I lose my voice and it sounds like I have run a marathon and I am shaking by the trauma. It is so hard to explain. This nerve cross talk may be from the damage GABA, the multiple nerve blocks and surgeries, and over twenty areas of pathology on the spine, or a combination of these and the past thirteen years.**

FINAL THOUGHTS AND OPINIONS

My story is not a cut and dried pudendal neuralgia (PN) or persistent genital arousal disorder (PGAD) story. Medications, procedures, seventeen nerve blocks to the PN and clitoris and the operations have led to new diagnoses and new morbid symptoms. I would give anything to go back in time and have the twenty-four-hour satanic acid like burning that could have been dimmed with Lexapro after the Amitriptyline caused dystonia. Just a simple change in a class of medications may have stopped thirteen years of hell. Amitriptyline a tricyclic antidepressant (TCA) used off label which worked for four years for the constant burning pain, could have been substituted for Lexapro a selective serotonin reuptake inhibitor (SSRI), known to stop the burning I was experiencing from the damaged PN.

However, at this point in 2010 I was going through withdrawal and dealing with the addition of new schedule IV and V medications in a downward spiral unable to process any decisions. Keep in mind in 2010 I had no smart phone to research medication or forums to join in the palm of my hand via the internet.

The Lyrica I have been on for over a decade has cause problems with my sight, and memory. The benzodiazepines prescribed for sleep, damaged the Gamma-aminobutyric (GABA). The antidepressants given to stop PN signals from going to my brain, caused dystonia and a myriad of other permanent life altering problems.

The illness-dictated sedentary life style and medications caused osteoporosis, allodynia, and central sensitization; the list is endless. The symptoms range from traditional pain to feelings of light touching under the skin, to feeling like someone is shoving me with one finger under the

left shoulder blade as if to push me along. From the front of me to the back, I am fighting morbid neuropathies. Most of my days are spent icing, applying various prescription and over the counter medications, creams, and patches to negate symptoms. If I can get the PGAD and aforementioned symptoms to a place where it is manageable enough to leave the house, it's like winning the lottery.

This endless dance of the morbid constant PGAD and various neuropathies is the domino effect of the initial illness, (the damage to the pudendal nerve) and thirteen years of all that I have endured in the journey to try to cure PN and PGAD.

I am better than day one in 2006, after the first injury to the pudendal nerve which caused never ending acid burning and electric shocks. This continued for four years masked by amitriptyline and clonazepam, until the amitriptyline cause dystonia and both meds were discontinued. Valium was prescribed for the dystonic tics. The withdrawal from these meds with the addition of Valium caused every extreme reaction known and came close to ending my life.

Pudendal nerve blocks (PNB) with Depo Medrol where then administered in 2010 causing persistent genital arousal disorder (PGAD). Which resolved after the first PNB and yet remained after the second PNB a month later. It is believed Depo Medrol, the steroid used off label in the PNB caused further damage to the nerve triggering PGAD. Research states that Depo Medrol can cause crystals which can damage the nerve, as it was designed for muscles and not nerves. Many doctors refuse to use this steroid with PNB because of this. It is now 2023 and after two surgeries, multiple procedures and on Lyrica for nerve pain and Lexapro to derail PGAD signals from going to the brain, I am officially permanently disable with PGAD.

Never agree to do any surgery, procedure, or take any medication without researching like your life depends on it, ask questions, ask "what ifs", ask other patients about their experiences. Do not reinvent the wheel and do learn from their mistakes, and network, network, network. I encourage everyone to keep thinking outside the box for answers. And when you experience something positive or negative, be sure to post it. Your post may become the answer a patient is looking for. For instance, "cutting the clitoral nerve causes the inability to orgasm, but does not stop arousal in the clitoris". These are obscure but important pieces of information for other patients and for researchers.

This post is from a site which is no longer available. It was one I read in 2017 which I was so grateful for. I searched for the author because she validated so many things I was feeling, but was unable to find her. I hope that her post will continue to help others as she has helped others around me understand that I am not alone with my symptoms. The following was lifted from my research paper entitled, THE DOMINO EFFECT OF PUDENDAL NEUROPATHY".

A patient on psas.nl in the Netherlands describes widespread neuropathies with sexual over tones (which could possibly be central sensitization), and PGAD causing a domino effect of symptoms under, "My experience of PGAD" (February 25, 2017). She mentions that her PGAD

symptoms are worse in the summer. This may be because patients are outside and more active in warm weather, and physical activity can irritate the pudendal nerve exasperating symptoms. The patient writes in part, *"I think I have had symptoms of PGAD since I was about 16. It's been extremely disruptive to my life. People who haven't had it cannot possibly understand it. Even I forget just how bad it is during the times I don't have it. **It's impossible to imagine the madness of being on the brink of orgasm for days and weeks unless you are right there, going through it right now. My symptoms are unrelenting pelvic aches and being on the edge of orgasm - constantly. I don't have any of the other health issues that are sometimes reported alongside PGAD. I don't get urinary or vaginal infections. I don't need to urinate frequently. I don't have 'restless legs'. I have no pain during sex. I have no other body pains. I also experience intense sensations in the length of my spine and in my uterus and entire middle section, including my ribs. Any touch, no matter how light, in any of those areas, sends off crashing waves of sensation to my genital region, and often those sensations are so overwhelming that they take my breath away.** Obviously, this is embarrassing in public. I have to try to steady my breathing and pretend like nothing is happening - when all the while my body is on fire and my genitals feel like they are physically turning themselves inside out in an attempt to reach orgasm. That is the worst of it - that feeling as if my vagina is turning itself inside out. I don't know how else to explain it. At night, I have to ask my partner not to touch me while I'm sleeping - not even a hand on my back. Because the sensations it produces can be enormous, and can even wake me from sleep. This thing - PGAD - often wakes me from sleep all on its own."* Continuing she states, *"It's like needing to pee and your bladder is about to explode but you just can't pee. If you can imagine that going on for hours and days and weeks, you might begin to understand. **Men seem especially dismissive - I've seen things they write online in response to PGAD where they say 'Welcome to my world - the world of a normal male sex drive'. These jokers seriously have no idea. If that were vaguely true, men would have erections 24/7. Also, your penis would end up feeling as if it was turning itself inside out. And your balls would pain for literal days and feel like they were going to explode.** I don't consider that I experience 'flare-ups', because the sensations are always there - just some weeks they are duller than others and I can ignore them. Summer is harder than winter. Sitting brings on more symptoms but walking when the symptoms are bad is awful in a way that is difficult to describe - all I can say is, try to imagine walking along a street while you're on the brink of orgasming (an orgasm that never completes, so you just stay there, at the brink) and while everything in that area is swollen. Anyway, posting this because today is a very bad one for me. I can't work. I can't think. My body is running its own marathon. **A couple of times today, I wished I would die and this would end.** Even though this forum isn't very active, the posts that have been left help me feel like I'm not alone in this. I hope this post helps someone on a bad day, too. **When you feel as if you can't bear another hour of this torture, know that it will pass and you're not alone. Today, that's what I'm trying to tell myself. Because the 'me' that I am when this thing passes knows that's true."***

As for thinking out side the box, in 2010 after the second pudendal nerve block which gave me never ending PGAD I wrote to doctors in Turkey, Israel and the USA who were studying various venoms from scorpions, and spiders to snakes, to see if the venom which caused paralysis could be used to stop my agony. I was desperate and crashing from three medications and nothing was off the table.

I have seen the names of world renown doctors on television, in primary source papers, and in articles in the NY Times and the New Yorker and have done a deep dive on the internet to find their contact information and written them for help. Many times, these doctors will write back and if they cannot help in some instances, they have suggested colleagues who can. Even as I write this in 2023, I have just emailed three of the world's top doctors studying the pudendal nerve and or associated neuropathies. These email addresses were given to me by a doctor I saw on 60 Minutes (an American television show), who not only gave me his colleagues contacts but told me to tell them he sent me. So, again network!

I am grateful that I have come this far. But sadly, the research indicates that patients who have been on benzodiazepines for over six years as I have, have an enormous increase in the chances of experiencing dementia. I believe at age sixty-five, between the Lyrica effecting my memory, and my history with prescription Clonazepam taken only as prescribe but for six years, (for sleep caused by pain and later PGAD) the clock has already started.

But the truth is, with or without the possibility of dementia, because I am disabled with PGAD and on Medicare and Medicaid with no assets or family, my life will end in a nursing home with only a sheet between me and a stranger for privacy.

The staff will be geriatric nursing aids (GNAs) or temporary agency GNAs who do not know me or anything about PGAD. The horror of having to explain PGAD to them will be mortifying, if I am even able to explain at that point. These are now my "what ifs", this is now me "thinking outside the box".

I once was in the Johns Hopkins University Bay View Hospital waiting room while I waited for my room to be prepared. My chart was picked up by non-medical staff checking patients in, and I was stared at across a room with only me in it. I was snickered at as my chart was passed around, to the point where I went up to see what they were reading, and it read "arousal disorder". So, when I am 80 years old, if I am in a nursing home my complaints of arousal may be seen as amusing or dementia confabulation or worse, and as a result I may be medicated even more.

These speculations are based on over five hundred hours spent as a visitor with my mother who has a master's in English and is high functioning, in a memory wing in five-hour long visits, interacting with staff and other patients.

The nursing home has chemically restrained her with medications because they are too short staffed to use behavior modification. I know the horror of these places first hand. They are over medicating patients and they have new temporary employees every week in the wing, which are hired from agencies. If that too is my future, my disorder will be seen by hundreds of strangers who are neither nurses or doctors.

There will be no private freezer to keep the frozen water bottles which I need every night. They will give me ice in a baggie which will not stay in place and will melt in an hour, as that is what they have done in every hospital stay I have endured.

Medicare and Medicaid will not pay for the over-the-counter products I need to survive; like roll on icy hot liquid, compounded lidocaine and expensive Salonpas hot gel patches, all of which I must have to balance the arousal and central centralization, in areas explained in the timeline. I know this because all my doctors have written to the government to appeal every time Medicare and Medicaid has denied paying for an over the counter (OTC) or compounded medication which my doctors all deemed medically-necessary.

In a nursing home as an older patient, I will never sleep again. Nursing homes for the most part drug their patients at 6pm after dinner, so they will sleep at 7 pm and get up at 8 am. At 8 am, I will be only four hours into getting to sleep as I now go to bed at 4am due to the damage to my GABA and the side effects of my PN medications and the illness itself.

Nursing homes wings are loud and that especially applies to the dementia wing where I may be, because of my family history and benzodiazepine damage to my brain.

I will not have the basics to survive like privacy, over the counter medications and sleep. If I wake before my body wakes up organically, the chances of arousal increases. Sleep is the only time I am free from PGAD symptoms. The charge nurse that most Medicare nursing homes hire will not understand that without those patches and creams I will lose my mind in a half hour.

What woman could survive wide spread arousal, deep in the ligaments, on the clitoris, right and left labia majora and minora, mons pubis and every area in between to include the sacral plexus? What PGAD patient would tolerate even an hour with anyone in the same room, especially a stranger, with GNAs running inside the room and out?

I have lasted this long knowing I had a way out. To be clear my PGAD is wide spread, satanic and unpredictable, but I do not mean suicide. There are countries who understand chronic illnesses, and death with dignity, and that is my "way out".

I live with a stranger, and every week is almost a carbon copy of the one before. This illness has stolen my independence, hopes, dreams, and potential. I live with no adrenalin rush from running or playing tennis. I have missed nine nieces and nephew's weddings, ball games, plays, birthdays, Christmases, and my father's 80th surprise birthday party with relatives I had not seen since I was little. I have missed adventures with my friends.

I was unable to take my mother in, who has dementia, to help her in her last years. I cannot plan anything as I am a PGAD time bomb. My college degrees are worthless.

My creative endeavors have kept me alive and I strongly suggest finding something you love to do even if it is not something you would have chosen in your old life. Keep only positive people around you and do not just limit stress, ban it from your life completely.

Do what you must do to stay here as long as possible as they are finding new ways to deal with nerve signals all the time. I will continue to stay as long as possible using the coping skills I have for the past thirteen years. You are not alone and your fears are as important as your hopes. Again, my arousal is more widespread (as you can read in my timeline), then a main stream PGAD patient. So, I would be very hopeful in your shoes. I am still fighting 13 years out, so if you have PGAD and are reading this, I believe in your life time the medical community to include scientists doing brain and nerve research will come to your rescue. Do not give up but do speak up. Breathe in, hold, breathe out and then repeat.

1

<https://www.benzo.org.uk/manual/bzsched.htm>

2

<https://www.benzoinfo.com/2018/04/28/how-benzodiazepines-mimic-chronic-illness-and-what-to-do-about-it/>

3

https://www.healthtap.com/user_questions/638936-how-to-deal-with-benzo-withdrawal-xanax-klonopin-clonazepam-ativan-valium-etc no longer available

4

<https://www.mayoclinic.org/diseases-conditions/dysarthria/symptoms-causes/syc-20371994>

5

www.utdallas.edu/research/FAS/diagnosis.html
no longer available

6

[Pathophysiology of Peripheral Nerve Injury During Regional Anesthesia \(nih.gov\).](#)