

## **PE1651/PPPPP**

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I am a 41 year-old cardiologist from the United States, and I have been harmed by benzodiazepines. I was prescribed Xanax 0.5 mg three times daily as needed by my primary care physician during a health crisis in August 2015 (severe dry eye syndrome). I started out taking Xanax 0.25 mg nightly only as a sleep aid, as my eyes felt like sandpaper and were interfering with my sleep. After only a few weeks, I began to experience severe anxiety during the day, which required more Xanax (up to 1 mg per day). I began to think that I was going crazy. I also developed a tremor and underwent an extensive neurologic evaluation, including a lumbar puncture that resulted in a severe spinal headache and an ER visit for a blood patch to stop the leaking cerebrospinal fluid. Xanax was never suggested as a cause for my tremor, although my dose relieved the symptoms of the tremor. It got to the point where I needed to dose every 6 hours as the Xanax would only last a few hours, then I would experience severe symptoms like difficulty breathing, chest tightness, and inability to swallow. I lost about 15 pounds (I am only 5'3" and got down to 115 pounds). I looked like a skeleton. I was terrified to be alone. I would wake up at night after 3 hours of sleep with my heart pounding and in a sheer panic. After doing my own research, I discovered that I was experiencing inter-dose withdrawals and had become dependent on Xanax. I tried to taper off directly, but the symptoms were too strong. I spoke with my primary doctor and told her that I was sure I was dependent on Xanax and wanted to taper off. She told me that my problem was all anxiety as I had only been on the Xanax a few weeks, so I could safely cold turkey. She basically treated me as if I were crazy. I knew that I would be unable to cold turkey given the severity of my symptoms. She gave me a prescription for Lexapro which increased my symptoms, and I stopped it after only 3 days. She also gave me enough Xanax to complete a rapid 2-3 week taper. Fortunately, I found the Ashton manual and Benzobuddies support group online and scheduled an appointment with the best psychiatrist in town. I brought him a copy of the Ashton manual and told him I was interested in tapering off Xanax by crossing over to Valium. Fortunately he listened to me, agreed that I was indeed dependent on the Xanax, and he agreed with my plan to taper off with Valium.

During a period of about 5-6 weeks, I crossed over to Valium while weaning off the Xanax. Once I was on a stable dose of Valium (15 mg daily), I began my taper. I have been tapering Valium since January of 2016 and have proven to be very sensitive to withdrawal symptoms. I am currently down to 4 mg daily. I experience a host of benzo withdrawal symptoms (I had none of these prior to starting the drug), the worst of which include a pounding heart, tremor, shortness of breath, severe nausea, low appetite, insomnia, muscle spasm, severe acid reflux, severe constipation, confusion, anxiety, depression, and suicidal ideation. I constantly live in a state of terror and "fight or flight" mode. My life is quite frankly a living hell. There have been times after cutting my dose where I have been in so much despair

from my symptoms that I have considered ending my life. My mind constantly tells me that I will never make it, and that I will never get better. The only thing that has kept me going is the fact that I have a husband and 7 year old daughter. Honestly this is probably the only reason I have not ended my life. Just to be clear, I do not have any intention of ending my life. But I still am left with these feelings of impending death. I have persevered through much and will continue to persevere. I have learned and am still learning to deal with my symptoms. Fortunately, I made the decision to become a stay at home mom several years ago so I do not have the requirements of my work. There is no way I would be able to handle them from either a cognitive or physical standpoint. I had to hire a nanny to help me with my daughter and household chores as I do not have the energy to get everything done, and there are many days I am not safe to drive. My life is currently severely impaired. I cannot travel and I struggle to do day-to-day tasks. My entire family has been severely affected by my withdrawal syndrome.

As if benzo withdrawal were not enough, I was diagnosed with stage 2A breast cancer at the end of April 2016. I had just made a cut to my Valium dose 3 days prior to the diagnosis, and instead of going back to my current dose at the time, I stuck it out. I spent a week with little sleep, awake in my bed all night shaking with terror. I underwent double mastectomy with tissue expander placement on 6/1/16. The surgery was successful but recovery was much harder for me due to the taper. The tissue expanders were placed under my pectoralis major muscles and I went for saline fills every 2 weeks (I required a total of 6 fills). The pectoralis muscle spasms were excruciating and were exacerbated by my Valium withdrawals. Although I held my Valium dose constant before and after surgery, I experienced increased withdrawal symptoms about 3 weeks after surgery (I am assuming the anesthesia and other post-op meds increased the Valium levels in my system temporarily, and I went into withdrawal when the meds wore off). Again, I spent a week with little sleep, lying in bed shaking, all my muscles spasming, including my painful post-operative chest. My symptoms were so bad that I considered up dosing, but after discussing with my psychiatrist, I decided to ride out the storm and was able to stabilize. In all this time of tapering, I have never once taken an extra dose or increased my dose of Valium. I fortunately did not require chemotherapy or radiation, or I'm not sure how I would have been able to deal with it in withdrawal. I was started on the hormone blocker tamoxifen which has somewhat complicated my taper due to the removal of estrogen from my body. It's interesting that cancer has been nothing compared to the horror of withdrawals, and I have heard that from several other cancer patients I have met along the way.

I am writing this testimony for the petition to Scottish parliament regarding an inquiry into prescription drugs because I want to stop this from happening to more patients. I am angry about what has happened to me, and to so many other people all over the world. I am a member of the web forum Benzobuddies, and I have met so many people that were put on these drugs by their doctor without being informed of the

possible consequences. I will tell you as a physician, that we are not trained about the severity of benzodiazepine withdrawal syndrome or the differences between the half lives and potencies of the various benzodiazepines. I attended medical school at the University of Texas Southwestern in Dallas, Texas, where I graduated Alpha Omega Alpha (top 5% of my class) in 2001. I did my internal medicine training at Washington University in St. Louis, Missouri. Both of these are highly respected medical institutions. I was taught that benzodiazepines are potentially “addictive”, that they are not a long-term solution, and they need to be tapered off if used for more than a few weeks. But I was never educated about things like inter-dose withdrawal, tapering methods, severity of the withdrawal syndrome, and difficulty in discontinuation of the drug. These were not drugs that I used in my everyday practice as a cardiologist, with exception of IV sedation for a procedure. I thought I was safe by taking a low dose of Xanax for just a few weeks and could come off fairly easily. I was mistaken. If this can happen to me, a physician who graduated at the top of her class, it can happen to anyone. I bristle when I hear the term addict in reference to these drugs. I am not a person with a history of substance abuse, nor do I have a tendency towards addiction. I am tired of putting these poison pills in my body. But unfortunately, I am chemically dependent, and the drug that is poisoning me must be tapered slowly to keep me from becoming extremely ill.

I propose that there needs to be better education in medical schools and among practicing physicians, especially in the fields of primary care, psychiatry, and oncology where these drug are used frequently. I also think there needs to be better regulation of the prescribing of these drugs and it should be mandatory to obtain informed consent from the patient. I will leave you with this thought. On my pharmacy pick up window, there is a sign that reads “Must show ID for all controlled substances for pickup”. I have picked up my Valium prescriptions monthly since January 2016 and have never once been asked for ID. No ID required for a drug that sudden discontinuation can cause seizures and death. No ID required for a drug that is considered to have more severe withdrawal than from heroin. No ID for a drug that has been implicated in numerous deaths from overdose (often in combination with opiates and for which there is now a black box warning from the FDA). No ID for a drug that has caused numerous suicides from the sheer horror of the withdrawals. Things need to change. I am not the only one struggling with this horror right now, and this madness must be stopped.