

PE1651/FFFFFF

Anonymous submission of 1 February 2018

RE: Psychiatric medication damage from Benzodiazepines taken AS PRESCRIBED.

I am a wife and mother of 2 young children who has traveled the world and has both a bachelors in Chemical Engineering and a Masters degree. Prior to my experience below, I was a stay-at-home mother and a wife. I volunteered at my child's school, drove my children to extracurricular activities, volunteered at church, traveled overseas with my family, and lived a happy and fulfilled life.

In early 2013, I was prescribed Klonopin (a Benzodiazepine also known as clonazepam) for muscle twitching by a physician hospitalist at the world renowned Cleveland Clinic following admission for the flu. Lab tests later revealed the muscle twitching was most likely due to magnesium, other minerals, and B vitamin deficiencies as noted by a private Doctor. After my first dose of Klonopin, I lost all sense of balance and developed extreme gastritis, unable to walk to the bathroom. 3 weeks later after only taking .5 mg of Klonopin once per day, I tried tapering off the medication as per my GPs direction over a several week period. As I lowered the dose I developed extreme nausea, inability to swallow, extreme muscle spasms, burning skin, horrifying anxiety (which I had never had before), suicide ideation (which I had never had before), extreme rage, Akathisia, inability to speak or write, complete loss of motor function to the point that when readmitted to the hospital the neurologist thought I had Guillian Barre Syndrome, which he later determined I did not.

I nearly seized and died had my GP not called my husband later at home and told him if we thought it was the Klonopin, to reinstate the full dose. Within an hour the symptoms had subsided and I was able to walk and talk - temporarily.

In our attempts to re-try tapering at a much slower rate, I threw up daily, had severe weight loss, and could not get out of my bed to go to the toilet, having to use diapers at the age of 40. I was bedridden for 2 years following this trying to find information as to what was going on with me, only to find the truth online and not in a physicians office. It took 2 years to find a physician who had read THE ASHTON MANUAL and was willing to taper me off slowly at the recommended rate of less than 10% per month of my prescribed dose. I have been completely disabled physically, mentally, and emotionally by this drug ever since. My family has been shattered in the path of this drugs' destruction of me.

I was NOT given informed consent as to the extreme addictive nature of this medication even taken short term, nor the extreme debilitating and life threatening nature of trying to slowly and safely taper off - which takes months and years as confirmed by my current neurologist at the Cleveland Clinic, who is educated in the matter.

Most recently my neurologist has diagnosed me with "medication induced akathisia" and "dystonia". He has also seen this in patients who seek him out due to

antidepressant withdrawal symptoms. He apologized to me for what the medical system had done to me. He is the first doctor in the 17+ I've seen that has said this. My neurologist is one of the heads of neurology at the world renowned Cleveland Clinic in Cleveland, Ohio, USA. He is also an adjunct professor at several of the major medical schools in our city, and has a long list of accomplishments. He also sits on several medical advisory boards.

Even with all this expertise and knowledge, at EVERY visit that I see him, I BRING HIM more information regarding benzodiazepines that peer support groups and forums have researched and found to be helpful for the central nervous system damage caused by benzodiazepines. He has been incredibly grateful for what I share with him (both on benzos and antidepressants) and he always shares it with his medical students. He tells them that "If they do not understand the severe nature of the side effects of benzodiazepines and antidepressants, or what is required to safely taper off of them - they should never prescribe them in the first place". He knows this firsthand not only from me, but from other patients who have sought out neurological diagnosis for their symptoms, which were in fact due to Benzodiazepine and antidepressant iatrogenic illness. I am grateful this man is listening and spreading awareness where it counts (to other physicians) with the goal of hoping to save people's lives.

Currently I have 4 doctors - most of whom I have had to educate myself along with the help and validation from my husband, because most doctors would not acknowledge that my symptoms were from benzodiazepines. I am fortunate they have compassion and have watched my journey and have put their egos aside to learn from me, as a patient. All of them have said thank you and that I am THEIR resource for information. That they are not taught this in medical school and that when they look at their patients, they now recognize so many of them are suffering from either benzodiazepine withdrawal syndrome or antidepressant withdrawal syndrome. Had I not shared this, by their own admission, they would not have known.

This is ludicrous, in my opinion. That highly educated medical professionals can so easily write prescriptions for drugs they know very little about, and then must be educated by their patients about those same drugs. Physicians NEED to start listening to their patients. They NEED to start asking hard questions of the pharmaceutical industry and holding them seriously accountable. Benzodiazepine Dependence and side effects and withdrawal symptoms have been known for decades. This is not a new problem. The facts have been intentionally brushed under the carpet for far too long.

My story is not rare. It is shared by millions across the globe. You only have to look to the many support groups formed on social media to verify this truth.

Over five years later, I am still tapering and unable to work, unable to care for my children, be a wife, a mother, or even be myself. I have developed food sensitivities, medication sensitivities, blood sugar dysregulation, inability to walk and in a wheelchair, loss of words, slurred speech, and many more disabling symptoms. At the moment, all of my physicians are trying to help me decide how to proceed. They have very little insight and have entrusted me to try to find the best

option possible for my body and outcome as they know I have more information than them.

I am also in the unfortunate position of being a type 1 diabetic, and have been for many years - incredibly well controlled (until benzodiazepines), having seen some of the best Endocrinologist's in my area for many years. Because benzodiazepines destroy the glucose and insulin response, and cause malabsorption issues in the gut, they make predicting blood sugar responses nearly impossible. Add to that, benzo withdrawal causes severe cognitive impairment, and many days I am unable to think clearly enough to calculate how much insulin I need to bolus on my insulin pump for my carbohydrate intake.

My incredible endocrinologist, who knew me before I was prescribed benzodiazepines by the hospital, is amazed I am still alive and now says they should never be prescribed to diabetics or anybody that needs their brain to survive - which would seem to me to be everyone that is alive. I am stuck in an impossible position daily where my life is threatened - not because of my Diabetes, but because of how the benzodiazepines have incapacitated my ability to manage my diabetes safely. It is heartbreaking and humbling to know that today may be my last because of this medication.

My husband has had to hire full time people (out of pocket with no medical or insurance help in this matter) to try to make sure that my life is not lost due to this. But we have been through nearly 50 people to try to find help, as nobody wants to deal with the dynamics and horrifying symptoms that the dystonia and akathisia add to this mess.

My husband has had to miss countless days of work because of my withdrawal symptoms and has been demoted as a result. His stress level in worrying about me, our children, and our finances has led him to having multiple stress tests on his heart because he thought he was having a heart attack. I worry about the effects this disaster has had on his health and his future in providing for us. I worry about the trauma this has caused for him as a caregiver and spouse and parent. He has no support system. Friends and family are dismissive and lack empathy for the severity of our dilemma.

My children are unable to participate in after school activities because we are unable to afford a nanny just for them. Their social network is at a bare minimum as a result of this. So is ours. They have witnessed things in my journey that no child should have to watch as their mother struggles to communicate with them or even hug them or care for them.

We are isolated from meeting new people, and all but a couple friends have left us. Our families have abandoned us. Our church has abandoned us. People that my husband shared my story with label me as a drug addict because they are misinformed about the horrors of these prescription drugs. I am unable to drive or leave the house. I am unable to hold long conversations with others. I am unable to care for my elderly parents, or even travel to visit them in their deteriorating state. I am unable to parent my children in the way I had so deeply wanted to. I am unable to support or share in a deep meaningful relationship with my husband because of

my cognitive and emotional distress - for years now. I thank God he has stood by my side. Many I know are not so fortunate. This is not a life for any of us. We are all in survival mode on a daily basis. And it is pure hell.

Benzodiazepines must be taken off the market - and for those who are on them they must be safely tapered over months and years ONLY if the patient chooses. Both benzodiazepines and antidepressants need strict INFORMED consent. People have absolutely no clue what they are getting into and neither do their physicians. In the US 1 in 5 people are on psychiatric medications. Our society is being silently manipulated and destroyed by the very drugs they believe are supposed to help them.

This medication has destroyed my and my family's life. I eat, breathe, and sleep trying to research ways to get out of benzo withdrawal alive to no avail. I know that if I had never taken the Klonopin AS PRESCRIBED by the doctor, I would be fully functional today - contributing to my church, my family, my children's development and future, and my community.

Please read the attached information and educate yourselves to the dangers of benzodiazepines so that you can be part of the change that is necessary to save millions of lives and families across the world.

Other well-respected websites with valuable and current information:

- Benzoinfo.com
- W-BAD.org
- Benzo.org.uk
- cepuk.org/

Thank you for having the courage to ask questions on a countrywide scale which will hopefully have worldwide impact. Thank you for taking the time to listen to patients' stories, and to read my experience. I pray my sharing of my story will in some way help to prevent harm to even just one person in this world, and that my and my family's suffering will not have been in vain.