

**PE1651/LLLLL**

**Diane Dunsmuir submission of 27 January 2018**

I am a United States citizen, but my husband is a Scottish citizen living here in the state of Texas. Benzodiazepines have affected us in several ways over the past two years. I hope that these drugs are better regulated for their recommended short-term use, that the consumer is given information about potential side effects and withdrawal syndrome to make an informed choice about continuing use for long-term, and that the medical system will offer proper guidance for the withdrawal of these drugs.

There are three problems with benzodiazepines that have gravely affected my life: The first is that the drugs are frequently prescribed long-term when they are only approved for short-term use, which is clearly documented in the prescribing information as two to four weeks, Secondly, the torturous and disabling withdrawal and cold-turkey withdrawal symptoms, and lastly the patient is not informed of the possibility for withdrawal syndrome, kindling, and potential for dangerous poly-drug combinations.

I was put on Lorazepam during a hospital stay for seizures, which were later found out to be due to an adverse reaction to medications. The doses varied during my two week stay with doses that reached as high as 5 MG in a single day. By the time I left the hospital I was physically dependent on the drug. No one at the hospital had mentioned anything about withdrawal syndrome.

I had tried to taper at my doctor's recommended rate of .25 MG, but when I did I had a major increase in symptoms and seizures. This caused me to go back up to my prescribed dose of 3 MG a day. Instead of suggesting a smaller taper rate, which now I know from The Ashton Manual should have been a 10% reduction, she prescribed 20 MG of Paxil, an SSRI. This poly-drug combination caused me sedation, hypersomnia, clonus, and spasticity of my feet, in addition to other side effects I had experienced on just Lorazepam, including dysfluency, aphasia, apraxia, tremor and sensory overstimulation. I found out months later that due to my unique DNA I metabolize both drugs too quickly and they caused neurotoxicity.

My symptoms continued to increase and I ended up in another hospital because I was having problems walking and was having seizures regularly. During my hospital stay, unbeknownst to me or my family, the doctor removed my Lorazepam prescription. I started having more and more seizures and I began having oromandibular dystonia and later torticollis dystonia. My face and neck were involuntarily contracting when I spoke, ate, drank, or tried to get up. My tongue folded up in my mouth and at the height of the contractions I would start to seize. There were times that the nurse had to flip me over so that I could breathe. If I was not in the hospital when this happened I might not have survived.

My family called the doctor and an on-call doctor came and gave me a rescue dose of .5 MG Lorazepam. Throughout the night I still was unable to eat, drink, or speak, without having dystonia and seizures, but they were not as intense. My whole body ached and was drenched with sweat, I had anxiety, racing thoughts that were

random and scrambled, a terrible headache, and though exhausted, I was unable to sleep.

The next day, I had a nap and I awoke feeling better than I had since I had since I had been put on the drug. I was able to eat and drink again without issue. When the doctors came they told me that I had been taken off of Lorazepam and due to my extreme symptoms they decided to reinstate me at 1 MG. My speech returned to normal and my tremors significantly lessened. I returned home feeling much better.

I went to a new doctor to help me taper and she gave me the same instructions to reduce my dose by .25 MG. I had my first seizure since the hospital stay. After some online research I found Benzodiazepine withdrawal support groups, websites, and the Ashton Manual and I started to educate my doctors. Using the advice from these sources I was able to reduce my dose more comfortably, but I still had many withdrawal symptoms.

My symptoms (in no particular order) varied throughout my withdrawals and consisted of: Headaches, muscle pain, chest tightness, palpitations, night sweats, electric shock sensations throughout my body, sensitivity to light and sound, muscle contractions, jerks, spasms, and discoordination, insomnia, heartburn and gastrointestinal reflux, bloated stomach, chest, and face, edema of ankles, sore eyes and seeing flashing lights especially when closing eyes at night, blurred vision, blepharospasm, memory loss and problems with encoding and memory retrieval, cognitive impairments including, decision making, multitasking, math, planning, and organizing, confusion, restless legs, tremor, agitation, aggressive behavior, irrational rage due to misperceptions, cortisol surges, adrenal insufficiency, inflammation which caused frequent infections, brain fog, slowed cognition, and continued speech issues in relation to withdrawal.

Because of my DNA metabolization of Valium, I was unable to switch over, as is recommended by the Ashton Manual due to the half life of the drugs. My doctor had me try to switch to Librium instead. He instructed me to take both Librium and Lorazepam for two days and then drop the Lorazepam. When I took them both I became completely sedated. I decided not to switch over and I didn't take another Librium dose. A week later I started having new symptoms of severe brain fatigue and shutdown. It was like my brain would get overstimulated and then go into safety mode, only allowing for the bare minimum usage. When this happened even lights and sounds were too distracting. The only relief and recovery for this is sleep, lots and lots of sleep. Safety mode lasts hours and sometimes days depending on the extent of my brain fatigue. My neuropsychologist describes this like when the power goes out and you only have a backup generator. You only can use it for the things most needed, like the refrigerator and heat, whereas, with my brain, I can't use higher level processes like word finding, memory, planning, organizing, multitasking, and my speech becomes impaired while my involuntary functions like breathing and heart rate are unaffected. I can talk and walk but processing is much slower and I can only give the simple answer.

This I still have now, minus the sensory effects of light and sound, one month off of Lorazepam. This damage may not repair so easily. I had been kindled by the increase and then abrupt drop of the additional benzodiazepine. Doctors should be

aware of this potential phenomenon. Not only does being kindled cause damage to your brain, but it causes your body to go into a hypersensitive state. Withdrawal becomes agony and takes far longer.

I used to be an activity director in nursing homes and memory care, but I have been out of work for two years because of this nightmare and I still suffer from disabling cognitive impairments. If I had been informed about the potential for withdrawal syndrome and had been instructed how to properly taper, I wouldn't have remained on the drug, I would have never been cold-turkeyed, poly-drugged, or kindled. Doctors need to be educated on the potential effects of these drugs so that they can properly guide and support people in coming off of the drugs. I've read that there are over 900,000 people worldwide with prescriptions for Benzodiazepines. Someday, they too, will need to navigate the withdrawal process and I hope and pray we have better systems in place for them.