

PE1651/QQQQQQQ

Sonja Styblo submission of 27 January 2018

I was prescribed a small dose of Clonazepam as needed to help with sleep difficulties related to post traumatic stress. I took less than prescribed and not on a daily basis.

I began to have brief transient moments where I would feel either oddly disconnected from my environment or I would wake up and frighteningly feel like I was coming out of my skin. I did not know it at the time, but I was experiencing interdose benzodiazepine withdrawal and it would end up leading me down a path of polypharmacy. For four to five years, I was prescribed five psychotropic drugs including the antipsychotic sedative Serequel/Quetiapine.

All my original “symptoms” worsened and new ones began to appear. I was becoming disabled. It was obvious that the drugs were not doing what they had promised, so I took what I considered to be a very large chance and decided to come off of them, because at that point I had nothing to lose.

Oddly, for the first month off I was out of it but I was not uncomfortable. Then “all hell broke loose.” I started having severe muscle spasms which were visible to others all over my body including my face. I became so shaky that I was unable to hold utensils. I began to experience a severe vertigo that felt like my brain was on a ship swaying around in a storm. I could not walk straight. I looked similar to those rare and severe recovering alcoholics who experience a ‘dry drunk walk,’ except that this did not start detoxing off severely abused alcohol — this began at a month off a prescription drug taken as prescribed, and lasted for the next two years. I also had visual hallucinations that distorted people’s faces, changed my body in the mirror and caused me to see things which I knew were not there.

I went to my prescriber, emergency rooms, my general practitioner and walk-in clinics. Nothing came up on tests and I heard many different explanations. My psychiatrist told me that the problem was that I did not have enough friends. One doctor frighteningly told me that I probably had a brain autoimmune disease, and another asked that “didn’t it seem more likely that the absence of drugs unmasked an underlying condition rather than the drugs causing the problems?” His hubris and groupthink-inspired point was dead wrong. Please don’t make the same mistake.

Seriously underestimating neuroplasticity, they all agreed that it would be impossible to be affected by these drugs this far off of them. A few Youtube videos from early survivors and a Wikipedia page, no less, were the first things to point me in the right direction.

For the first two and a half years off of Clonazepam I experienced many effects of having a damaged central nervous system. “Rebound anxiety” does not do justice to what people with this syndrome experience — what we go through is beyond the bounds of what is natural, and I find it hard to believe that anyone who has not experienced it would understand. It was as if my adrenaline surpassed its crest and my fear response was constantly activated. The insomnia was truly some kind of sick torture; for months and months on end I only slept for one or two hours a night and it was not as if I could have taken something to alleviate it. Some mornings I would experience night terrors with grotesque figures but I would be fully awake. I experienced sensory overload where I was hypersensitive to light, noise and any kind of stimulus in the environment. I had to wear sunglasses at all times and often closed myself off in a dark closet for periods of time. For me, one of the worst symptoms was an ever-present terrible nausea that persisted twenty four hours a day for years.

Also of great concern was my cognitive state, especially because I was unsure of where this was going. Put it this way: at four months off I was attending a psychiatric hospitalization day program and it occurred to me that I was unable to do ‘the math’ involved in trying to calculate crossing the busy intersection near its building. Navigating public transit was very difficult for me for a long time because of my mental state. I would end up alone in unintended destinations around the city.

The central nervous system of course does not end with the physical and mental but extends to the emotional as well. I was labile at times, experiencing crying spells or hysterical laughter for no reason. Mostly, I was severely depressed. There were many days where every few minutes I would have to tell myself not to commit suicide, both from the uncomfortableness of a CNS on fire but also from depressive haywire rumination. If not dangerously depressed, I was anhedonic. As one ‘benzo author’ noted about their experience, I too was for years physically incapable of smiling naturally or even on command; it was as if I had lost connection to those signals or nerves. I also suffered from persistent derealization and depersonalization.

Needless to say, any original post traumatic issues were not helped by these drugs — they were only hindered and then joined by this new horrific experience.

During my lengthy benzo withdrawal syndrome, my mother fell very ill for a year and passed away. That is crucial and precious time with her I will never get back. In our final time together I was largely a shell of myself, all because of a pharmaceutical drug. She left this world with a daughter whom it was unclear would ever be better or return. I was also unable to emote and grieve in normal health. These drugs do not “permit people to function normally in the world” — what they do is largely rob people of their humanity. I am no outlier. Contrary to the point that Dr. Carl Salzman made last year at an American hearing for benzodiazepine legislative reform that even caffeine causes withdrawal, these are the real-world consequences of benzodiazepines. For the many others who both consciously, and with less awareness, chose not to endure the ill effects or the torment of protracted benzodiazepine withdrawal syndromes any longer, I would also like to point out that caffeine does not kill people. Make no mistake: this is an easily preventable tragedy on a mass scale.

It has been four years and five months since I have been off of Clonazepam. I have only had about two years of relative health, with several residual effects. I am in my first year of social work graduate school. Additionally, I worked for a year as a mental health specialist in a renowned drug and alcohol detox program. These are both things that would have been utterly inconceivable on my drug regimen or in the several subsequent several following discontinuation. I saw the gamut of detoxes from every substance you can imagine at the hospital I worked at and nothing compares to protracted benzo discontinuation syndrome.