

PE1651/UUUU

Hilary Gardiner submission of 30 January 2018

I live in Brockton, Massachusetts, in the United States. I'm writing to share my story of benzodiazepine withdrawal.

I am speaking out as someone who, two years ago, was prescribed Klonopin for panic attacks by a nurse practitioner in Northampton, MA, who assured me that if I took the drug as prescribed there would be no issue (I was worried because I had heard about problems with benzodiazepine dependency and withdrawal before). I only took Klonopin for one month, as prescribed, before deciding to get off of it because one day it dawned on me that, while I no longer had panic attacks, I also didn't feel much of anything. My prescriber came up with a month-long taper plan, which I followed to a tee. The mental and physical anguish that ensued is something I still can't put into words to this day, and was a thousand times worse than the anxiety I originally intended to treat. When I called my prescriber to tell her about my symptoms, which were disabling, she told me they had nothing to do with the Klonopin taper. At this point I literally had to conclude I was dying or losing my mind; my nervous system was constantly in fight-or-flight mode, I couldn't drive, my blood pressure and pulse were constantly extremely elevated, I had the worst headache of my life for days at a time, I couldn't sleep for days at a time, and I had vivid hallucinations when attempting to sleep. The level of anxiety I experienced is something I can't even put into words, and was deeply physiological and inescapable. It was as if the whole world and everything around me, however benign, was something deeply, innately terrifying, and my body was constantly responding to this threat regardless of all attempts to rationalize the experience. I found support groups online and discovered there were thousands of people going through the same thing, people who had taken the drugs as prescribed, and tapered slowly as instructed, people who were in excruciating anguish like myself, people whose prescribers also denied their experience, leading to even more suffering and then distrust of medical professionals. I also found out afterward that Klonopin is contraindicated for people with kidney disease, which I had at the time, and sure enough my kidney failure progressed very rapidly during the withdrawal, and before I knew it I was doing dialysis a lot sooner than my nephrologist or I had anticipated-within three months of the taper.

I was diagnosed with an auto-immune kidney disease at four years old and have been through dialysis and two kidney transplants in the span of seven years, at just 30 years old, but I can confidently say that the physical, mental, and spiritual anguish I suffered during withdrawal was unparalleled in its intensity. The weight of this admission, and the medical community's failure to acknowledge the scope of this problem, horrifies me to no end. Prescribers clearly don't know enough about the mechanisms of these drugs and the lasting effects they have on one's nervous and endocrine systems, and when patients report their experiences back to them, often in peak desperation, they are often met with ignorance, stigma, and condescension, as if their account of their experience cannot be trusted because they were prescribed the drugs in the first place. To deny the experience of someone in withdrawal is quite literally paramount to giving someone a dose of acid and then denying that it's the acid causing one's "bad trip"; it is utterly cruel and dangerous. I often wonder, if I didn't have access to the internet and didn't think to Google support

groups during the time of my withdrawal, what would I have done? If I never found out there was an end in sight, that it was in fact the withdrawal despite my prescriber's insistence otherwise, what would I have done?

The suffering incurred by the lack of information about these drugs is barbaric and causes long-term iatrogenic injury in many people. Our voices need to be heard so that prescribing practices change and vulnerable patients seeking help are not made to face symptoms exponentially and indescribably worse than the problem they originally intend to treat.