

## **PE1651/SS**

Claire Hanley submission of 10 January 2018

I have had sixteen years of my life stolen from me by benzodiazepine medication prescribed to me by my GP, latterly at 100 mg per day.

Here is an account of what it felt like in the acute stage of illness after tapering off the benzos.

"All I am is a collection of symptoms. As I write this my teeth continue to cut and bore into my tongue and cheeks. A mouth full of blood is something I've grown used to. I feel tightness around my head like a cheesewire about to slice my brain into two like it were a piece of Edam. I'm coughing all the time. When I walk the ground feels like a trampoline, soft and flexible but also soft as though the trampoline were covered in sand. The room feels as though it were spinning. Noise is magnified by a thousand, so is movement, so is smell, so is light, so is touch. My chemical sensitivities are raging. My hall was painted two days ago. I thought, despite knowing paint fumes can make symptoms worse, that I could open a window and it would be ok. I was wrong. Each inhalation of air smarts with pain. My throat, nose and ears are all red raw. Burning like they are on fire. I stumble to go outside for air, holding on to furniture as I go for balance. But it's cold outside and each freezing breath hurts. I am puffy in the face. Apart from the swelling, I have gained four stone since I started tapering off the benzodiazepines. The irony is that being fat is usually linked to a lack of self-control. I've steadfastly avoided all the food and drinks known to make symptoms worse. Caffeine, MSG, gluten, sugar, the list goes on. If I make a mistake and ingest the wrong foods I'd pay for it in severe symptoms for days. Yet with eating being my only source of comfort during this horror show I've progressively got fatter and it's still happening. My life is moving from bed to sofa and back to bed. I cannot go out. How could I in this state. With my senses being assaulted to this level, a small trip out no matter how small or brief would be, at best, an ordeal. I would not have believed these phenomena to be possible had I not experienced them myself. My body has become my own personal torture chamber. I do not know how much longer I will have to live through this. There is no way of knowing. I'm told it will improve gradually but there is no way to know. I used to make plans just in case I got better. I was an optimist at the start but I have long since realised that life is to be led not just day by day, but minute by minute. A week seems like a blink of an eye such is the long monotony of my routine. So I log onto Facebook for my only social contact. As I press 'like' on pretty images of the dancing groups I used to belong to my limbs jolt, electric shock sensations occur in my head arms and legs. My skin burns like it's on fire and crawls and itches at the same time. I have tried to keep up appearances on Facebook that I'm still me. But the truth is there is no space for such a luxury as a personality when all life has become is coping with symptoms. That's all I have become. A cluster of symptoms and odd phenomena that are so horrifyingly bizarre they defy description. The experience I'm going through is difficult for others to relate to. What people tend not to understand they reject.

During this process which I started over eighteen months ago there has been no let up. I have tried to convey what is happening to others but I was dumped from my former dance group due to non-attendance. They thought I could have attended

even a few rehearsals if I'd "just tried". A former friend got angry with me that I would not host a dinner party. I did explain I am not even cognitively functional enough to make a cup of tea without errors. This is something they could not relate to so did not believe possible. And another seemed irritated that I was "still ill". The fact is the way other human beings have hurtled away from this illness, anyone would think I had a disease as highly contagious as Ebola.

I know that my other friends online going through the same illness are experiencing the same isolation to varying degrees. Our lives are lived on Facebook and we are thankful it exists. While these symptoms rage on there is plenty of thinking time. Looking back at how our lives were blighted by the medication we were prescribed by our doctors. Unable to move forward with our lives due to the disability, caught in this helpless limbo of symptoms, there is plenty of time to see how our lives would have been different if we had not been injured by benzodiazepines.

There was a time, before I had started my taper, when the benzodiazepines were affecting my mood so profoundly that I thought of very little other than suicide. And yet back then, although suffering from symptoms of 'tolerance' I had my figure, I could walk, I was bubbly. I have far, far more to be depressed about since that time. A cauliflower leads a life more interesting than me! As the amount of benzodiazepines in my system slowly decreased I saw symptoms I thought were intrinsically part of me disappear. The night terrors have stopped, the constant suicidality has gone, the depression lifted. I was getting clear windows of the real me...coming back again. And these results spurred me on during the taper. It felt worth it.

But now in this acute stage there is a cruel irony. Having seen the negative effects of the benzodiazepine medication diminish and even vanish, my body and mind are now besieged with the symptoms of discontinuation. Brain injury and central nervous system damage have replaced the symptoms of tolerance to benzodiazepines. I try not to despair, I try to believe that things will get better as I'm told they slowly will, but this is an invisible ordeal. It is isolating, it is incommunicable, it is unspeakable, confounding, ever-changing in intensity and seemingly never-ending. It is like no other illness or disability commonly known. We struggle to believe it ourselves at times. How could our governments and doctors have allowed the pharmaceutical industry to do this to us? It defies belief that this could be happening, but it is. We are an inconvenient truth, suffering to such a degree that it seems difficult to understand how governments could have allowed the pharmaceutical industry to continue in this way. All some of us want now is to stop this happening to others. That's the only meaning some of us have left in our lives. So where help and support can be given, we'd appreciate it very much, if not for us, for future generations."

NB. Since the time of writing I am out of the acute stage of symptoms described above and am slowly recuperating and trying to rebuild what is left of my life despite the disabilities with which I have been left.

Please help the victims of this preventable medical disaster.