

## PE1651/LLLL

Heather Buchler submission of 20 January 2018

So far, benzodiazepines have taken a decade from my life.

In 2002, I went to a pain clinic for neck pain, caused I think mainly by stress and by working too hard, and I was put onto 2.5 mgs of clonazepam, a benzodiazepine, being assured by the respected physician in charge of the clinic that it was safe, and that he had patients on it for twelve years or more, with no ill effects. I did not know, but the doctor no doubt knew, that Australian government guidelines have been in place for at least twenty years that recommend for benzos a prescription period of no longer than four weeks. He also advised me that I could take anything between 1.5 mgs and 3 mgs each day, depending on how I was feeling, but I eventually settled for 2.5 mgs. I had no idea at the time that it is a very bad idea to go up and down on a the dose of a benzo, as it has the potential to peeve the nervous system even more than it already is, and it seems that the physician did not know this either.

I had no idea at the time that 2.5 mgs of clonazepam was equivalent in dose to 50 mgs of valium. I do wonder if the doctor knew this. If he did, he sure didn't tell me.

The clonazepam did help at first, but after a couple of months, I began to develop pain elsewhere in my neck and in other parts of the body. The original pain went away, thanks to my osteopath, but I was getting tight, sore areas throughout my body, and a very sore neck, but in a different part of the neck to where the original problem was. I had no idea at this stage that it was the clonazepam that was causing the trouble. I was getting worse, and did not realise that it was the drug that was the culprit.

I muddled on like this for a few years, continuing to deteriorate physically, but I finally determined to wean off the medication, which I did by mid 2006, in my own way, with no knowledge of the Ashton manual <http://www.benzo.org.uk/manual/contents.htm> or of the well-informed benzo support forums that could be found on the internet at the time. By that stage, I had stopped going to my osteopath, who had been a tremendous help, as I was just too sore to be touched. The upper part of my neck was very very tender, and even I could not touch it without feeling substantial pain. I also had back pain, and the thoracic area had sharp, constant pain. By this time, I had also stopped going to the pain management physician.

The five month taper off 2.5 mgs of clonazepam was very unpleasant, but doable. I experienced pain and suicidal ideation all the way through it. I did not know at the time that these are typical benzo withdrawal symptoms, and that they were temporary. Two weeks after being off the clonazepam, I felt considerably better, and all the pain went away. What a relief that was! My nervous system still had some repairing to do, as I had stiff muscles, so I stayed at home for three weeks, and then after the three weeks were up, I went shopping in the city.

On my way home, a car rear-ended me while I was stopped at a roundabout, giving way to oncoming traffic. No real long-term damage was done, but I had an adverse reaction, and my GP advised me to take something to calm down the nervous system. Namely the drug that I had just come off, clonazepam. I was reluctant, but

as I had tapered off it without too much trouble, and as he advised that it was more benign than other painkillers, I agreed. It is interesting that he seemed to regard clonazepam as a painkiller. So I was put back onto 2 mgs of clonazepam, and then 5 - 10 mgs of valium were added in.

To my great dismay, this caused all kinds of problems, mainly pain and very tight muscles, but also other distressing symptoms, such as panic attacks, that I had never experienced before. It was clear that clonazepam and valium were making me sick.

In 2007, the GP who had put me back onto clonazepam moved away from the practice, so I went to another GP for help and for a plan to get off the stuff. She saw how badly the drug was affecting me, and she gave me what turned out to be a very unsafe "cold-turkey" plan to withdraw from the drug. Her plan seemed safe to me at the time, as she had me dropping by .5 mgs every three days. She offered to get me off within three days, but I opted for two weeks. I had no idea at the time that a year or two was a more reasonable, safer time frame.

I still didn't know about Professor Heather Ashton, the leading expert on benzodiazepines, or about the benzo support forums on the internet. I still trusted the doctor.

On the night of my last dose, my family took me to the emergency department of the hospital, as clearly something was going wrong. The hospital kept me in overnight, I think to watch for seizures, and then I was transferred to a private psych ward, where I was to spend the following seven weeks. Somehow I had lost the ability to dress, feed, shower myself and walk. I needed nursing, but the other inmates were able bodied, and the psychiatrist who had admitted me instructed the nurses not to coddle me, so for much of the time, help was refused, and I often had to wait until a more sympathetic nurse came on to the next shift and took pity on me.

I was given a walker to practice walking again, and was ordered out of bed. I was also expected to attend CBT sessions with the other patients, who I think had mostly landed there as their medication had pooped out on them, and they were staying until they stabilised on their new cocktail. I was in enormous pain, and found CBT sessions practically impossible to attend, and eventually I just gave up on them. They were of no help anyway, nor were the sessions on drug addiction. I had no desire to ever take a benzo again. This was not like an addiction to alcohol or street drugs - it was a physical dependence caused by the changes that the benzo had made to my body and brain.

I was ordered to receive visitors. While I had been at home, I had asked people not to visit, as I was just not up to it, but suddenly when I was in a hospital, everyone thought it was OK to visit, and I had no control over this. This was very, very hard, as I had trouble talking and being friendly and it was exhausting and distressing, although without my husband's constant support and encouragement, I would not have fared nearly so well.

During the time that I was in the psych ward, I still trusted the doctors, and I agreed to take some some medications which I was advised would help with the tormenting symptoms that I was enduring. I absolutely refused any AD's or SSRI's, as I had very bad experiences with these in the past, but I was given Ambien, a benzo-related sleeping pill, and was assured that this was not a benzo, and that it was safe. I was also put onto Largactyl, an anti-psychotic, but after a week or two, I started to develop dangerous side effects from this, and was abruptly taken off it. A few days later, Lyrica and massive amounts of Panadol and Ibuprofen were added in. Then to top it all off, I was given Xyprexa, another anti-psychotic, which I took for a short time only. This was given to help me sleep - like swatting a fly with a bulldozer.

I was experiencing a great deal of anxiety, and was advised by hospital staff that this anxiety was the cause of the pain, and that I needed to get this anxiety under control. I was informed that pain and anxiety were not benzo withdrawal symptoms. Wrong! The "benzo expert" nurse there assured me that benzo withdrawal involved depersonalisation, which was so horrible that it could go on for a few weeks. She had no idea that actually six months or sometimes even years is more often the case - certainly not mere weeks.

I came home after seven weeks, no better, in enormous pain, and my husband was doing everything, including helping me to dress. I was unable to do much at all and didn't want any visitors, as I felt very withdrawn and reclusive. I was also seriously suicidal and could not be left alone (typical benzo withdrawal symptoms). The psychiatrist (the one who had admitted me to the psych ward) insisted on seeing me every day for a while in an attempt to keep me safe.

My husband then did some searching on the internet and found that I had essentially been "cold-turkeyed" by my GP off the benzodiazepine, and that I would be like this for quite some time. We had finally found a benzo support forum, where my husband posted my story for me.

By then I was also addicted to 12 mgs of Ambien, which I had started while in the psych ward, and which we later discovered was just the same as a benzo. On advice from the benzo forum, we informed the psychiatrist that this was in fact a benzo-related drug. On learning this, she told me to drop it, maybe by taking half for a few days and then stopping it. I was unable to, as it was helping a little to relieve some of the horror, and her plan was way too fast.

Apart from visits to the psychiatrist, I didn't go out anywhere for a long time.

A moderator from the benzo forum then sent me a message and advising me to reinstate to a benzo, valium, as there was not really any other choice. Reluctantly, I reinstated to 20 mgs of valium to do a slow taper off it. The reinstatement had a detrimental effect on me, as I found it impossible to stabilise on the valium. A couple of very concerned members of the forum were by then writing to me by private message, and they urged me to up the dose to the original 40 mgs that I had been on. (The 2 mgs of clonazepam that I had been on equates to 20 mgs of valium.) We persuaded the psychiatrist to allow me to do this, so I increased the dose to 41 mgs. (The extra 1 mg was my mistake.) The effect was dramatic, and I became

much worse symptom-wise. The valium had really turned on me, and was actually causing huge, unbearable, constant pain. Despair, depression, violent vomiting, whole body jerking, followed by panic attacks, insomnia, cog fog, screaming tinnitus, fear of being alone, and many other very unpleasant symptoms. I really didn't know what to do, and became pretty desperate.

I was advised by the forum that somehow I had to do some sort of a taper. With the help of my new GP, I started on Tramadol, an opiate painkiller, which I took on board to relieve the unbearable, unrelenting pain from valium. during what was a very traumatic, brutal taper off valium, where I had to cut regardless of symptoms. I then did the same with the tramadol. The taper off valium took almost 2 years and I finally made it in April 2009. I had tapered off the Tramadol by September 2009, six months later.

At one stage, I was writing to Prof Ashton, who also gave me advice as to what to do. I passed the advice and the Ashton Manual on to the psychiatrist, who gradually became informed about benzos and how to safely withdraw from them. Ashton offered several times to speak with the psychiatrist, who turned down her offer.

I spent a few years on the internet, helping out as a staff member on benzo forums, assisting others who found themselves in trouble with benzos, and who needed support and advice. As I was not sleeping much, scoring anything from zero to four hours' sleep a night for over a year, this was something positive that I could do with myself, day or night, and it gave me company with others who understood what this was like.

The pain has now gradually morphed more into muscle rigidity, which is still very debilitating and distressing, but the actual pain is not as bad as it used to be. Many of the other symptoms have gone, but I still feel fragile, and I still have loud, constant tinnitus. My worst stuff is extreme muscle tightness, especially in the upper back and neck, although it is along all the spine. Even my skin is tight, as well as the deeper muscles. They grab and pull and claw at me and torment. Some days, it is difficult to walk and balance as they are so tight. It never lets up. Some days it feels as if the skin is being stripped off my back as it pulls and claws on (I think) where the muscles attach. My osteopath is a great help with the physical discomfort. He feels that the muscle rigidity is dissipating, but that the nervous system is still on "overdrive".

My husband has been looking after me for a lot of this time, although I am gradually becoming more independent and I am doing more. I walk a lot. I enjoy cooking, knitting, listening to music and gardening. I'm listening to audio books. I'm starting to do Tai Chi, although this is hard going. I can drive again, short distances. Sitting is still difficult.

For me, it has been important to push the envelope a little, to step just a little outside my comfort zone, to find a new level of comfort and function, although I would not have been able to do this in the early days post-taper, and some days this is still not doable.

This experience is not unique to me. There are untold numbers of people worldwide who come to grief with this class of drugs. The upside to this story, if there is to be one, is the many wonderful friendships that I have made, from Melbourne to Ballarat, to the wheat belt of WA, and the Gold Coast of QLD, from New Zealand, to Virginia, to Spain, Ireland, Turkey, the UK, Egypt, Massachusetts, Oregon, North Carolina, New York and Florida, all with similar stories to tell.

<http://www.benzo.org.uk/amisc/chabradford.pdf>