

PE1651/AAAA

Barbara Bell's written submission of 12 January 2018

It was about 12 years ago that I became unwell. I had gone through a tough time and a sudden bereavement of a family member which caused me to visit my GP. I couldn't sleep and was struggling. I was prescribed diazepam and continued to take it as prescribed over a long period of time. I didn't take a large dose and sometimes didn't take any at all. I never realised how the drug was gradually impacting on my health. I started to feel unwell but trusted my GPs and never thought of the drug causing the problems.

I suffered from dizziness and I would get feelings as though I was about to pass out. I had heart arrhythmia, faintness, gastric problems and low blood pressure. I felt a wreck and couldn't do anything at all. My previous busy life was now in tatters. Prior to this I had a career, was a walk leader and had many hobbies including painting and golf. All these had been snatched away and worse still I couldn't do things for my family; I was too ill.

It got to a point where my GP sent me for tests to rule out a brain tumour and heart problems but all were negative. Still I became more unwell with the most horrible symptoms. I tried acupuncture, homeopathy, anything to help this mystery illness. It wasn't until I found the guidance given in the Professor Heather Ashton Manual that I realised that the drugs I was being prescribed were in fact exactly what were making me so unwell and that the drug was highly addictive.

I cried with relief when I read the manual because all the symptoms of tolerance were exactly what I was suffering. Little did I know then that this was just the beginning of my journey to hell.

I immediately started to taper off the drug by following the withdrawal guidance in the manual. I was delighted and at first didn't experience too many problems. My GPs were not familiar with the correct withdrawal procedure or the ill effects of the drug, so I reduced with the help of the manual and also the charities that I had by now found online.

When I reached almost the end of my taper the whole thing snowballed. Maybe I had needed to slow down at the end, I didn't know, and the only guide I had was the manual. Then I experienced the most horrific symptoms of panic attacks, agoraphobia and crushing rib pain. By now I had been forced to give up my job as a medical interviewer, the drug had impacted on every area of my life. My family were worried and I was terrified that the drug had trapped me and I really didn't know what to do.

By now my surgery had become involved and they said that they didn't have the expertise to deal with withdrawal. Desperate, I sought the help of the drug and alcohol service. They didn't seem to have any knowledge of withdrawal from prescribed drugs and I was given a withdrawal schedule that was even faster than the one I had just attempted.

Because of this I asked to see the consultant who had drawn up the schedule for advice. He met with me and told me that coming off the drugs was like a loose tooth. Saying, "you can either wiggle it for ages or extract it quickly". I was by now desperate and so decided to follow his advice and, despite warnings from the charity, I entered his detox unit. I just wanted to be free of the drug and so I undertook his regime of a 'slow' withdrawal of 1mg every 2 days. (In effect this detox is like a cold turkey.)

The unit was for illegal drug users and for alcoholics and I was the only person there at the time coming off a prescription drug. I went into the unit on two occasions and on the second occasion came off completely. I was given drugs to stop me from having a seizure while I was being detoxed and at the end the consultant said, "well you did really well and you didn't die, you can go home with my blessing".

By now those who had been taken off hard drugs in the unit were recovering while I was getting progressively worse every day. How I got home I will never know, but my husband came for me and by this time I had lost memory and coordination. The pain was horrific and my ears were ringing constantly. I felt as though my ribs were being crushed and I could hardly breathe for the pain. It was just like those patients coming off heroin but unlike those my suffering didn't go away-it got worse.

The pain became progressively worse over the next weeks until it was unbearable. I was desperate and phoned the unit up many times. No one would help, I was laughed at when I mentioned The Professor Ashton Protocol to the unit manager and the consultant refused to even speak with me. He had issued orders to my GP that I was never to be given diazepam again and I was no longer his patient.

To take the drug again was the last thing I ever wanted but by now I had been in touch with the charity, who told me I needed to go back on the drug and taper properly as the pain could get even worse and I was also at risk of a seizure. The charity spoke with my GP who did everything to help and once again I was put back on the drug to taper for the third time. By now I wondered if I would ever be free.

The pain had spread to my legs and feet as well as my body and I couldn't even stand up long enough to brush my teeth. My fingers bent backward and became stuck, my hair started to fall out along with my eyebrows, I lost weight and my eyes couldn't stand the light. The rapid detox left me so ill that I was now completely house-bound helpless and bedridden for two years.

For two years I relied entirely on my husband who had to do everything for me. I also had the support of withdrawal charities who spoke with me daily, their encouragement and words ("you WILL recover") kept me going. I realise now that the way I was taken off was far too rapid and this is why I have suffered such devastating consequences. The charities and the Ashton protocol all recommend a very slow taper.

After almost two years I finally took the last 1/4 mg of the drug. I hated even seeing the drug and despite still being in agonising pain, I had made it off the drug at last.

It is now almost five years since that day and 7 years since the horrific detox. Over this time I can now walk again and my hair and eyebrows are back! My memory and concentration are improved along with the tinnitus, which comes and goes. However, I am still suffering from horrible nerve pain in my body. Three of my fingers are still stuck and concentration and sleep are still affected. I know I still have a long way to go.

If anyone had told me how a prescribed drug could cause this endless suffering I would never have believed it. Despite that, I am alive, hopefully recovering, and I have won the hardest longest battle I could ever have imagined.