

PE1651/IIII

Rosalind Jones submission of 12 January 2018

I'm over five years off forty years of prescriptions for Temazepam and other benzodiazepine drugs given for insomnia following a total hysterectomy in my twenties. I am now 72 and still suffering intense symptoms but have received little medical help or support over this time. My suffering was never recognised and I was only offered further drugs which made me a lot worse. My full story is on the Beating Benzos' website.

I've lost my life to benzodiazepine drugs and urge you stop all this horror and end all the suffering these drugs cause.

This is a description of the early stages of my withdrawal from benzodiazepines which I endured with no support. All I was offered at this time were further Psychoactive drugs....

I want to try and put the acute stage of withdrawal into words but this is no easy task. This stage is going to be a little different for everyone who has to endure its relentless, unforgiving passage.

Panic attack doesn't go half way towards describing this. A panic attack ends within minutes maybe hours but the acute stage of benzo withdrawal may last weeks or even months with little respite.

I stopped the Nitrazepam sleeping tablets on November 22nd 2012. I write in my journal, "*Must let panic pass, adrenaline will wear off, don't worry if not sleeping, just go with it all for the moment as I will get better*". Wise advice but as the weeks passed so it became harder and harder to just let go and watch it all rage around from the safety of my bed.

There was only the Benzobuddies withdrawal site to help see me through all this and to understand what was happening. I believe this process is the GABA receptors in the brain trying to come back on line so to speak. The brain is left in an acute deprivation from a drug that has caused these receptors to be down regulated. I don't understand the full medical explanation but suffice to say that my brain was suffering a severe physiological reaction and was trying to repair from years and years of this down regulation. There is no research only many, many sufferers putting their own experiences into words. The bible is the Ashton manual written by Professor Heather Ashton and the only accepted work on Benzodiazepine withdrawal. Although Professor Ashton is now elderly she did email me with encouragement and some wise words on sleep when I had suffered sleep deprivation for a week. No sleep at all just relentless pacing of the house as I was unable to even lie still in bed.

An adrenaline attack would often hit during the night for me. This is when our cortisol levels are at their highest and having to deal with the surge of cortisol plus an already weakened body from withdrawal gave me intense symptoms. I liken it to being dangled over a precipice from which any minute I could be hurtled into oblivion. I actually felt I wanted to be hurtled into that oblivion and die quickly. Dying

would have been the easy way out. My heartbeat increased to uncomfortable rates. I shook and sweat poured off me. My whole body stiffened, as my muscles were painful as if stretched taught by the adrenaline. I was vomiting, had unrelenting diarrhea and water drained off my body. My whole system was over revving as if the accelerator was being pressed and jammed down. I was scared, dizzy and my blood pressure climbed at these times. I spent my nights walking around my house, in and out of rooms chanting positive affirmations such as 'This too will pass'. There was little respite for five weeks and during this time I was ringing around for any support I could find to just keep me alive.... The Samaritans but they had no knowledge of withdrawal; emergency doctors but one even said, 'Benzo Withdrawal was all a myth', how I wish he could have suffered and experienced the reality of his so called myth; The Bristol Tranquilliser project, who were immense help and enabled me to keep sane; a dear lady who runs a group for sufferers in Cornwall and has always been there for me; Mind who again had little knowledge of withdrawal at this time and so on. Literally anywhere I felt could give me an explanation and help get me through this dreadful phase. There were periods during the day when I may have had a brief respite as my exhausted body gave up and I rested on my bed distracted by an inane television programme but these were few and far between.

Just writing about this phase has started me shaking and sweating as the memory is recalled. The best help I received was again from the website Benzobuddies where I would write post after post shouting out my fears. There are 11,000 sufferers on this site and many in the acute stage as I was. My journal records some of the worst moments, *"Restless and agitated, very cold but sweating, must float through and keep calm, whole body vibrating and legs twitching with violent contractions, sick, stomach pain and movement, trying to breath through, heart palpitating, mustn't fight it....."*.

It was if my body was no longer a peaceful, calm haven of which my brain had control. It was now inhabited by some kind of force with a will of its own. This force had taken over every part of me and determined whether my muscles would function or not, whether my heart beat evenly or erratically, whether my thoughts were positive or negative, whether my stomach could digest food, whether I should sleep or stay awake all night, whether I was boiling hot or freezing cold, whether I laughed or cried. It took over my very being and I had no say in the matter. I just had to go with the flow and let it all happen without putting any obstacles in its way. Eventually it let me go for a brief respite into normality only to take over again when I was least expecting it. At this time I was aware, and still am, that the slightest trigger could allow it access so I could tolerate no drugs, supplements, sugar, caffeine, processed foods, exercise or just plain stress. I had to tread very carefully.

At about three to four months off the worst of these symptoms let go and I entered a phase of windows and waves.

The windows and waves continue to this day. Now 62 months later I still have a severely sensitive system unable to tolerate any drugs, supplements or certain foods. I'm also unable to live a full, normal life and doubt I ever will now. Let Scotland lead the way in preventing this sort of thing ever happening again with full training of doctors, helplines and medical support for those of us who suffer for a lifetime.