

PE1651/NNN

Submission from Pamela Wilson of 9 January 2018

I am a member of the campaign for Prescribed Harm U.K. I have been badly damaged by my GPs long-term prescription and cold turkey withdrawal of benzodiazepines. For over 37 years I have suffered the increasingly hellish consequences of brain damage, due to c27 years of repeated benzodiazepine prescription. My suffering is significant, as are the abnormalities on my brain SPECT scan and both were unnecessarily caused by my doctors' wrongful prescribing. As my constant hellish suffering, "sinister" neurological losses and obvious deterioration continue – and despite all my pleas, my doctors prefer to ignore the cause and damaging consequences. They dismiss all evidence, refuse expert contact and facts presented and instead cover the prescribed harm of chemical poisoning by the word "psychological". Despite bringing relevant information from the Ashton manual, and personal contact from 2 well recognised benzodiazepine experts, both before and after the seizure event, my neurologist still refuses all expertise.

Yet my medical records prove that a psychiatrist first wrote to my GP in 1985, stating that the symptoms I described and physically displayed were all due to the severe and prominent side effects of the benzodiazepine medications. Prescription was to be carefully withdrawn and stopped completely, adding that I did not suffer "true" anxiety or depression. That did not happen and yoyo prescribing continued on and off for another 25 years. Then in 2006 I was diagnosed with the benzodiazepine condition of Post Acute Withdrawal Syndrome (PAWS) by the global expert Prof C Heather Ashton and again in 2008 with the severe effects of Protracted Withdrawal Syndrome (PWS). Prof Ashton contacted my GP directly to confirm and explain my severe suffering and she also tried to make contact with my neurologist. She kindly sent specific information to my GP and neurologist and explained how each of the host of medications prescribed had only exacerbated the effects of brain damage. She also warned them of her concern for my cold turkey withdrawal and the dangers of seizures, particularly as my head symptoms and electric zaps were increasing. Therefore it is completely wrong and deliberately misleading for doctors to ignore my benzodiazepine history and the life-changing seizure event. Instead they label the significant and dramatic physical changes, constant torturous consequences of "sinister" ever-progressing neurological losses and deterioration - as psychological. All my suffering for over 37 years directly relates to the prescription of benzodiazepines. This chemical poisoning has been further exacerbated on 2 very significant occasions. In 1998, my neurologist ignored the medically recognised side-effects of benzodiazepines and mistook my symptoms as MS. I then suffered repeated botched lumbar puncture attempts and 2 x Valium sedatives were wrongly injected into my spinal cord, causing horrendous consequences immediately and ever after. Then again in September 2016 my long-term neurologist said he'd now thoroughly researched all my history and benzodiazepines, and that a blood patch

would help if not cure my spinal cord problems. It quickly transpired this was not the case. Instead he greatly increased the torturous and quite unbearable chemical damage constantly passing from my spinal cord, into my brain and affects every part of my body.

For 37 years my long-term doctors very strongly deny that my suffering is in any way due to the effects of the previously prescribed medications.

They dismiss all benzodiazepine expertise and refuse any expert contact.

They dismiss the BMA statements (since October 2016 confirming that patients' suffering and "lived experience" is due to the brain damage and harmful effects caused by these medications). They have ignored the significant abnormalities on my brain SPECT scan, since 6th November 2013.

They record that my suffering and brain damage effects with very obvious physical changes, serious muscle distortions and sinister substance losses - are not related to the effects of the long-term medications.

They ignore the life-changing seizure event - and insist that the distinct damage and "neurotoxic cycle" that has constantly occurred since that precise event in March 2009, with much obvious physical evidence of increasing neurological suffering, damage, dysfunction and loss, and 8 admittances in 8 years to the neurology ward with worsening episodes of severe brain and spinal cord trauma causing horrendous painful and obvious muscle changes, distortions and increasing paralysis from the waist down, etc. - is all psychological.

Following the life-changing seizure event in 2009 Prof Ashton suggested I request a brain SPECT scan. In November 2013 my neurologist finally agreed. The scan showed significant abnormalities throughout my brain, likened to dementia and Alzheimer's and noted that possible lewy body dementia can't be ruled out. My neurologist said he was shocked by the amount of abnormalities throughout my brain and that this toxic damage could only have been caused by the long-term benzodiazepines, adding that he did not believe the diagnosis was correct - because he had withheld my benzodiazepine history. He assured me he would phone the radiologist and have a correct working diagnosis immediately. For over 4 years nothing has been done, yet as this neurological disaster progresses, my suffering and deterioration ever-increase. My complaint that requests my benzodiazepine history and facts of related brain damage be looked at, to allow a related diagnosis and possible support - is dismissed.

My story began in August 1981 when following a neck injury, I was given Valium as a muscle relaxant. Due to the new and random symptoms I experienced and displayed, the on and off, yoyo prescribing of benzodiazepines continued for almost 27 years. Due to the ongoing severity of increasing symptoms, I was also prescribed many other benzodiazepines and a host of other "psychotropic" /mental health

medications too. When I queried my medication I was told I had a chemical imbalance and would need to take the medication for the rest of my life. After 25 years prescription my GP severely restricted benzodiazepines. As the severity of my symptoms increased he insisted on a cold turkey withdrawal and refused to prescribe further medication. This led to increasing problems in my brain and spinal cord and resulted in a massive electrical explosion/seizure event, causing disastrous life-changing consequences to my brain and the initial injury site at the junction of my brainstem and spinal cord. The damage included - vertebral artery dissection, brainstem stroke, complete paralysis, locked-in-type syndrome, etc. As my neurologist refused all evidence, expertise and information on the effects of benzodiazepines and with harmful attitudes and ridicule ongoing, I requested a copy of my medical records. I was very alarmed to discover that psychiatrists first wrote to my GP in April 1985, telling him that I displayed severe and prominent side-effects and to withdraw and stop the medication completely, also that I did not have true anxiety or depression. Yet my GP's yoyo prescribing continued on and off for c27years. I also discovered that by his many attempts to deal with my severe side-effects, my GP prescribed every psychotropic drug in the book, 102 different trials, most with cold turkey withdrawals. He also noted that none of the prescriptions helped, but only made matters worse, by adding more symptoms to my "list of complaints", which he also noted were regularly presented at my frequent appointments. Due to the increasing severity of my physical symptoms particularly the rigidity of my muscles, that did not improve on the benzodiazepine muscle relaxant, but instead progressively painfully tightened, with worsening anxiety, 8 years insomnia, etc, and all for no apparent reason – my GP suddenly began to severely restrict my medications. I was later told to withdraw completely. He adamantly insisted that this time cold turkey was best and refused further prescription. Needing and having always wanted to get better, and not knowing of the "physiological dependence" or the dangers of cold turkey, I trusted my GP and followed instruction. While the physical symptoms and extreme rigidity in all my muscles very rapidly eased, new severe pains and the distinct feeling of electricity in my head kept increasing. Subsequently I suffered a massive and completely paralysing cold turkey seizure event in hospital, 13th March 2009. Following the completely life-changing seizure event, I was discharged home in a wheelchair and very effectively medically abandoned. I lived downstairs in a recliner chair for c5months and had to relearn how to function and move. Since then I have experienced constant levels of hellish neurological consequences causing increasing deterioration and loss. I have been admitted to neurology with 7 further episodes of paralysis, etc. Yet I still meet with serious denial and a refusal to accept or consider the recognised side effects and dangerous, harmful consequences of the previous long term benzodiazepines.

With no help at all in N.Ireland for patients suffering after withdrawal, and particularly as my symptoms were so severe, I made contact in England, initially with Una Corbett of BAT (Battle Against Tranquillisers), the late Pam Armstrong, nurse expert

of CITA (Council of Tranquilliser Addiction) and with Prof C Heather Ashton (the leading world expert on benzodiazepines).

Pam Armstrong had written many articles and a book on the subject of benzodiazepines and like Prof Ashton she travelled to various countries giving talks. Pam made contact with both my GP and my neurologist, and offered to visit Belfast and meet with them and their associates and give talks at the hospital to help educate doctors here. At that time N.Ireland had the largest percentage in the UK of patients being prescribed the medications.

Prof Ashton was quick to point out to my GP and neurologist, that after withdrawal the last remaining problem can be due to the original reason for prescription; in my case an injury of significance (which for 25 years was treated as just a neck injury, but in 2006 after referral to a neurologist, he informed us that from my descriptions and recorded history, I had suffered a tear between my spinal cord and brainstem, a vertebral artery dissection, a traumatic brain injury / T.B.I. Prof Ashton also passed on her concern for my initial injury, both to my GP and neurologist and warned that a cold turkey withdrawal could cause dangerous and life threatening seizures.

On the day he retired, my long-term GP (who Prof Ashton previously contacted on my behalf and explained the damaging consequences of his medications) - phoned me to say that he had simply forgotten the neck injury reason for my prescription and just thought I always had anxiety. In 1985 this same GP was first written to by psychiatrists and instructed to carefully withdraw and then stop the medication completely, having explained that my problems were all due to the severe and prominent side-effects. Since 1998, the same neurologist has been involved in my case, both with the mistaken MS botched lumbar puncture attempts and complications of the 2 Valium injections, Valium drip, etc. and the more recent blood patch with its increasingly unbearable consequences.

* Thank you for your time in reading my case history. While I apologise for poor quality writing and repetition, my hope is that my case can be used to help matters and to stop doctors' wrong and damaging labels, so that other innocent victims do not suffer unnecessarily, like me.

