

PE1651/H

Fiona French submission of 30 May 2017

A life destroyed by prescription drugs

I support the above petition because of my personal experience of consuming benzodiazepines and antidepressants for 40 years and enduring the most horrific withdrawal over the past four years, an experience which has been beyond imagination. I hope you will take the time to read my account. It is extremely pertinent. It demonstrates how PDD patients are being completely failed by the medical profession and by current Scottish (and UK) Government policy. Not only did my doctors fail to recognise my withdrawal symptoms, they are now colluding to deny that I have sustained brain damage due to withdrawal. I am left disabled, physically and cognitively, I have lost my independence and my retirement is in tatters. And not one doctor will discuss with me the fact that this has happened. That is something that I cannot forgive. If the damage had been worse and I had been unable to speak out, as is the case for many patients, no-one would ever know that I have sustained brain damage from benzodiazepine withdrawal. It would have been buried in my medical notes. I am outraged. And from meeting other sufferers online, I know that I am certainly not alone in my experience.

But to the beginning of my story: I was a high achiever at school and as a teenager, I became depressed. At age 20, I was diagnosed with **myoclonic epilepsy** and **prescribed the benzodiazepine, Nitrazepam**. I worried about its sedative effects but instead became hyperactive, lost a great deal of weight, returned to a state of pre-puberty and **within two months had tried to commit suicide for the first time**. My doctor did not recognise that I had suffered an adverse drug reaction and referred me to psychiatry. I then embarked on a 40-year "career" of seeing psychiatrists and taking anti-depressant drugs. No psychiatrist realised that I had had an adverse drug reaction. Most anti-depressants I could not tolerate. Only a few were tolerable but I doubt that any of them ever did me much good. For a time they suppressed suicidal feelings but they suppressed so much more than just that. They robbed me of the essence of life for the rest of my adult life but I was never aware that the drugs were the main source of my problems.

I was extremely unwell in my 20s. From my 30s onwards, things improved and I returned to College and University and spent 20 years working in NHS research, working closely with the medical profession and publishing papers in medical journals. My job was intellectually demanding. However, every day of my life was an immense battle to function physically and cognitively. **I felt alone and lonely every single day of those 40 years**. I believed that my "disabilities" were symptoms of "depression" and accepted that this was my life, I had no choice but to live this way. No doctor, GP or psychiatrist, suggested otherwise. I have lived a "half-life", being unable to experience normal emotions. Intellectual satisfaction became the substitute.

And to the horrors of withdrawal: I changed my GP practice in 2012. I was advised to consider coming off Nitrazepam. I asked if I would need another drug for myoclonic epilepsy. The GP did not reply. I voiced concerns about the impact of withdrawal on my mental health. The GP did not reply. I did not return for any further "discussion". I tapered off 5 mg over three months, unaware that this was too fast for someone who had been on the drug for 40 years.

By September 2013 I had become bedridden. I could hardly lift my head off the pillow, I felt so terribly, terribly ill. I could not describe the feeling, I was unaware it was coming from my brain. For the next three months I saw no-one. All my nerves were on "high alert". I had to prop up my head with extra pillows in order to eat. I was unable to read, watch TV, use a computer, listen to the radio/music and I was too unwell for visitors. I could not tolerate light or sound or anything next to my skin, including underwear. I made the occasional phone call but it was very difficult. My memory and concentration were shot to pieces. I slept a lot and was unaware of the passage of time. I had no idea what was wrong and felt too ill to contact a doctor. I saw my first visitors on Boxing Day. It was a very strange feeling as if the previous three months had passed in a flash.

In January 2014, I phoned the GP practice and requested a home visit, this was declined. I attended the surgery and **was advised it was not benzodiazepine withdrawal** but "depression" and was referred back to psychiatry. I was astounded that the GP could even imagine that the symptoms described above could be attributed to "depression". She seemed perplexed by the six month time lag between end of taper and becoming bedridden. She seemed unaware that the drug would be stored in my body after 40 years' consumption and that a time lag was perfectly understandable. I agreed to a psychiatric referral, thinking that a psychiatrist might be more knowledgeable about the subject of withdrawal. The psychiatrist agreed that I was not depressed but **told me my symptoms were unrelated to benzodiazepine withdrawal** and to "**think of it as ME/CFS**". He seemed unaware of the research by Professor Heather Ashton, the leading expert on benzodiazepine withdrawal. <http://www.lader-ashton.org/ashton-cv.html> I knew his diagnosis was wrong and I declined a subsequent referral to an ME/CFS specialist. I again asked my GP practice for a home visit but was told by a different GP to attend the surgery "to demonstrate my motivation". Clearly my problems were perceived as "psychological". I did not seek further medical help for three years, I was too ill to attend the surgery and I did not have the energy to argue the need for a home visit nor did I wish to be distressed by further refusals. I did however write to the practice in June 2015 outlining what had happened to me. I received a reply saying that the practice would be happy to see me to discuss any of these issues. I still did not feel well enough to go to the practice and it seemed that **the three GPs I had consulted so far had little understanding or knowledge of benzodiazepine withdrawal.**

Over 10 months, I gradually tapered off the antidepressant, effexor, feeling that I no longer required it. I doubt that I have been depressed for the past 30 years. My symptoms were drug side effects. I no longer have myoclonic epilepsy, the original reason for taking Nitrazepam. Since September 2013, I have suffered the most horrendous ordeal, tortured by my brain and body, day after day. Loss of sensation from the waist down, anal muscles that would not work, intense pressure inside my head, squeezing sensations inside my brain, unaware of the passage of time, unable to walk, unbearable nerve pain, seldom able to see anyone. Not one part of my body has been unaffected. **The only information, help and support available has been online from fellow sufferers.**

www.benzobuddies.org **But the Health Minister states the Government policy on PDD is adequate and has declined to commit funding to a UK-wide helpline as requested by the BMA and other medical bodies. She advises that PDD patients should consult their GP. Sadly this has been of no help to me whatsoever.**

Moving onto 2017, I experienced two jolts, one at the front of my brain, the other at the back of my brain. This seemed to jolt my brain back into some sort of "action" and I could feel my legs again. It was the first time since September 2013 that I felt able to make and keep medical appointments and to request appropriate scans and tests. I contacted my

GP and insisted on a home visit. The GP who advised me to withdraw from Nitrazepam visited me. He documented my symptoms but gave no opinion as to their cause, he only stated in his correspondence that it was my belief that they were due to withdrawal. However, he stated verbally to me that “benzos are poison” and he would never prescribe them. He also said he worked with drug addicts withdrawing from benzodiazepines. More recently, he has said that he cannot give an opinion in my case because he is not an expert. This is hardly credible.

I requested a private referral to neurology, thinking that perhaps a neurologist would understand my symptoms. The neurologist stated that they were **nothing to do with benzodiazepine withdrawal** but refused to discuss the subject. I realised that he was being dishonest. He diagnosed “neurological functional impairment”, which I might have accepted until I learned that “functional” means “no biological basis” and so there is a strong implication that the symptoms may be psychological. Indeed the neurologist tried to pursue this line with me and his letter to my GP also implied this. I was referred to a neurophysiologist for nerve conduction tests. He was very open about the extremely damaging effects of benzodiazepines but nothing was said in his letter about this, just that the test results were negative. I am waiting for an NHS neurology appointment but hold out little hope of a positive consultation or an accurate diagnosis.

Recently, I decided to consult with yet another GP in the practice, this was the 5th GP I have seen. **He said he did not want to get involved.** I appreciated his honesty. I assume now that the rest of the GPs in the practice will be similarly unwilling to get involved. I asked him if a report had been submitted to the MHRA documenting the extreme nature of the withdrawal symptoms I have endured. He said that no such report had been submitted but that he would submit one. Twice he suggested I do it myself but I insisted it come from the practice.

I have communicated with a leading expert on benzodiazepines in London. He has confirmed that my symptoms are consistent with benzodiazepine withdrawal. I am not officially his patient and am therefore unable to share his communication. I am now seeking a referral to Prof David Healy, Cardiff, Wales. He is a psychopharmacologist and international expert in adverse drug events, particularly SSRI antidepressants. <https://davidhealy.org> I know of two other patients in Scotland who have consulted with him. If I am unable to achieve an accurate diagnosis locally then I have no choice but to go further afield. I have lost an entire life to PDD and been left very sick and disabled due to withdrawal. The very least I deserve is an acknowledgement of the damage done and for that to be documented. As long as doctors misdiagnose side effects and withdrawal symptoms as signs of some underlying illness, there can be no accurate quantification of the problem. Deliberate denial is even worse. A helpline for PDD and specialist services are desperately needed, particularly as the prescribing rates of antidepressants continues unabated. Given the mounting evidence that these drugs are largely ineffective, this is absolutely shocking. Exactly the same happened when benzodiazepines were known to be highly addictive, prescription rates continued to rise despite prescribing guidelines limiting their use to a few weeks. Clearly, there is no mechanism to protect patients until it is too late and hundreds of thousands, possibly many, many more have been damaged. Something is very wrong and the Scottish (and UK) Governments have a responsibility to protect patients from unnecessary harm.

My only course of action now is to pursue the NHS complaints processes which is extremely difficult given my cognitive problems. To do this will cause further distress, putting more pressure on my brain and making recovery less likely. It seems that doctors

can apply any diagnostic label they choose, however misleading in order to obscure the fact that I have sustained brain damage due to benzodiazepine withdrawal. I prefer now to have a witness at all medical consultations. This is a tragic state of affairs.

Not once in 40 years did a doctor inform me of the potential damage to my brain and body from consuming benzodiazepines or antidepressants. This is unacceptable. Nor did they recognise that they were making me very ill. Nor did I have any meaningful discussion over the years about the difficulties of withdrawal and so my attempts at withdrawal were very brief and I simply reinstated. Even worse, I have received no meaningful help or support from my doctors (GPs & consultants) over the course of the past four years and it has now become absolutely clear to me that they are deliberately refusing to acknowledge that I have sustained brain damage as a direct result of withdrawal. My disabilities are physical and cognitive and their existence are rather difficult to deny.

I cannot discuss my concerns with any clinician because no-one will acknowledge or document what has happened to me except to state that it is my belief that it has happened. There is a deliberate attempt to discredit my account by focusing on my past mental health history which was largely caused by the drugs. Yet the Health Minister has repeatedly informed me that I should talk to my doctors about any problems with medication and/or withdrawal. I am utterly dismayed by her apparent lack of concern about this hugely important issue.