

PE1651/ZZZ

Stevie Lewis submission of 7 January 2018

My name is Stevie Lewis and I am the Petitioner for the “sister” petition to this one, raised in Wales. I am privileged to be campaigning alongside Marion Brown on this important and disturbing issue. I would like to thank the Scottish Petitions Committee for giving me this opportunity to make my voice heard and to give you some more information about the Welsh petition and my reason for raising it.

My story is similar to many that have been sent to you. I was prescribed an SSRI antidepressant in 1996, at the age of 41. I went to the doctor complaining of intermittent insomnia when I was away on business, plus PMT. I came away from the consultation with a diagnosis of being on the edge of a “clinical depression” and clutching a prescription for a drug which I was assured was not addictive. I was absolutely not on the edge of a nervous breakdown (I had to look up the meaning of clinical depression) and Seroxat turned out to be most definitely addictive. However, when my doctor stated these facts, telling me I had a chemical imbalance in my brain (also untrue), I believed him absolutely.

Dr David Healy, in his book “Pharmageddon”, describes how in the mid ‘90s, the drug company marketing teams were telling doctors that, for women, a critical marker for depression was insomnia. Seroxat was the new non-addictive solution rather than a short course of sleeping tablets, which is how this problem had been handled up to then (and what I was expecting to be given). Instead I ended up with a strong neurotoxic drug which has damaged my health – a complete overkill for the problems I presented. This has happened to many people, particularly women.

What followed was years of trying to stop the drug, and failing. At first I thought I was terribly ill with a major anxiety disorder. Eventually the penny dropped that I was experiencing withdrawal, which each time I stopped the drug would give me symptoms of insomnia, anorexia, indescribable anxiety, phobias, the list goes on. There was never any formal acknowledgement from my doctor that withdrawal existed or agreement that that was what I was experiencing. My only recourse was to take the lowest dose I could to keep the withdrawal at bay - I had to keep taking it in order to function. In 2008 I was found to have osteoporosis, a side effect of Seroxat as noted in the patient literature. In 2009 I developed a movement disorder. I lose voluntary control of my body and jerk violently as if I am having an epileptic fit, although I am awake. It is deeply unpleasant. This is considered by the neurologists I have seen to be either Medically Unexplained (MUS) or a Functional Neurological Disorder (FND). Most I have seen will not engage with me in the possibility that nearly two decades on an SSRI could be the cause. One neurologist was enlightened enough to consider it as an option and agreed to refer me to Dr David Healy in North Wales, who is an expert on SSRIs and Adverse Drug Reactions. His diagnosis was clear and immediate on hearing my story – an ADR between Seroxat and Alendronic Acid (for osteoporosis). He has seen the same movement disorder due to the same ADR in other patients before and since.

In 2013 I decided I had to stop the drug, whatever the withdrawal consequences, in the hope that if I did the movement disorder might stop too. I have been through four terrible years of indescribable withdrawal symptoms, and I am coming out the other

side. I now have a dysfunctional nervous system, I still have the movement disorder, and I have a dysfunctional digestive system which prevents me from eating a number of foods, or taking any supplements or drugs. My nervous system responds to any drug I try to take by making me jerk violently.

This is my motivation behind and justification for following Marion's lead and raising a similar petition in Wales. My petition calls for the Welsh Government to appropriately recognise and effectively support individuals affected and harmed by prescribed drug dependence and withdrawal. The issues in both parts of the UK are identical and it would be inspiring if both Petitions Committees and both Governments would cooperate in the provision of services to help those like me who had nowhere to turn except to fellow sufferers on the internet for help and advice.

In Wales we may be ahead of the game in comparison with the rest of the UK. There are already guidelines in place for the targeted reduction in the prescribing of benzodiazepines. This is monitored and reported annually and I wish to see antidepressants, especially the SSRIs, targeted and monitored in the same way. Also we already have an (tiny) NHS funded Prescribed Medication Support Service in place which has been operating for 20 years, in response initially to the benzo withdrawal crisis but latterly helping those with SSRI withdrawal too. Unfortunately, this service covers a limited geographical area of North Wales; I wish to see it expanded to cover the whole of the country.

Where government funding is going at the moment seems to be purely into Drug Misuse services. There is, both in Wales and Scotland, no recognition at policy level that patients who have become dependent on drugs which were taken wholly in line with their GPs prescribing guidelines require a different approach in order to withdraw from these dangerous neurotoxins. It is exemplary that society puts so much money and effort into helping people who misuse street drugs. However, we who did nothing other than believe our doctors and follow their advice deserve better than to be expected to line up at a Drug Misuse centre and be counselled to come off a benzo or SSRI in the same manner as one would a street drug. It can take months or even years, depending on the length of time it has been ingested, to withdraw from a prescribed benzo or SSRI. It is imperative that appropriate tapering guidelines become available UK wide.

My experience is, and my expectation continues to be, that any time I need access to NHS services my issues are distorted by the view that I took an SSRI for 17 years in total and therefore I have a history of "mental illness" which affects my physical health. What I want is for any nurse, doctor, specialist, consultant to look at my records and say, as a matter of routine, "yes, after long term use of an SSRI your physical body has been affected at a number of levels and we need to take that into account when treating you."

Please help us get that level of recognition within the medical profession. Our experience is that they don't want to know, they don't want to believe us and "it's all in our minds". Again I will say - we deserve better.