

P-05-784 Prescription drug dependence and withdrawal – recognition and support

Personal experiences received from individuals in relation to prescription drug dependence or withdrawal; March 2018

WT – By Stevie Lewis

Question 1.

My experience of prescribed drug dependence and withdrawal: 17 years taking Seroxat, 4 years withdrawal, some ongoing issues.

After trying a variety of non-drug treatments, I went to the doctor (in Bristol, where I was living at the time) in December 1996, at the age of 41, with intermittent insomnia when I went away on business, and PMS. I asked for some sleeping tablets to tide me over while I was away from home. I came away from the consultation with diagnosis of being “on the edge of a clinical depression” and a prescription for Seroxat, an SSRI antidepressant. I questioned my GP closely about the subject of addiction because I was aware at the time of the reputation of the benzodiazepines. He was reassuring, telling me it was a new class of drug that did not cause addiction or dependence. He said that I was ill and I had a chemical imbalance in my brain which would be corrected by the Seroxat. Its role was to rebalance my serotonin. When my doctor stated these facts, I believed him absolutely.

Whilst taking Seroxat, I was able to sleep when away on business, and pretty quickly I worked out that setting up my own management consultancy, which involved a lot of travelling, was not what I wanted in my life. I changed my life circumstances, felt very well and stopped the drug after five months. Coinciding with stopping the drug I became ill with nausea, vomiting and vertigo, which was so bad I went to the doctor and was diagnosed with labyrinthitis. It lasted about three weeks. It transpires this was my first experience of withdrawal.

A year later, after the death of my mother and three miscarriages, I felt anxious, I wasn't sleeping and I returned to the doctor for help. From a distance of twenty years it is obvious to me that I was grieving and needed someone to talk to. However, I was immediately offered and reluctantly accepted Seroxat again. There was no discussion between us about a plan for how long I should take it. Based on my previous experience I chose and planned a slightly longer course this time; I think I stopped after ten or eleven months. This time I not only had physical symptoms of nausea and dizziness, I also found I couldn't sleep at all, and I was terribly anxious, at a much stronger level than I had experienced prior to taking the

drug. The following diagnosis was that I was really ill and really did need this drug, because as soon as I started taking it again, I felt fine very quickly. At no time during my visits to the doctor were side effects or withdrawal effects mentioned. It was just accepted I was ill.

I moved to Wales in November 1999, registering with a new GP in 2000 and bringing to her symptoms and a diagnosis of a Generalized Anxiety Disorder. Except I was perplexed by the fact that when I was taking the drug I felt extremely well, but I only had to stop taking it for 48 hours before feelings of anxiety would start to build. So I would reintroduce the drug and 48 hours later, I was fine. A small voice inside me kept saying "this isn't you". There was nothing in my background or life that warranted such high anxiety, insomnia and weight loss when I stopped. The only other tablets I had taken in my life prior to Seroxat were antibiotics. I recognised that I had a predisposition to anxiety but it was always as a result of life events and seemed proportionate. What was happening to me was neither of those things. But I am strong-willed so I persevered in trying to come off the drug; the longest I lasted off it was seven weeks, to that point the worst seven weeks of my life. But that voice kept whispering in my ear and in 2002 I decided to look more closely into what I had been prescribed. I discovered via the internet that I wasn't desperately ill with an anxiety disorder that only Seroxat could fix. I was actually part of a community of Seroxat "users" who like me were ill with similar symptoms to mine whenever they reduced or stopped their medication. It was clear I fitted a pattern of addiction or dependency, due to the fact that the debilitating withdrawal was preventing me from stopping the drug totally.

What followed was years of trying to stop the drug, and failing. 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. There was never any formal acknowledgement from my doctor that withdrawal existed or agreement that that was what I was experiencing. However, whenever I asked for help from my GP it was provided. Using liquid Seroxat and small and smaller syringes, I became an expert in tapering. At my request, my GP contacted Glaxo Smith Kline to see if they would provide me with a more diluted version of the liquid so I could slow my taper further. They refused so I diluted it with water. I could never get lower than 1.78ml (approx. 3 mg – a therapeutic dose is 20mg). At 1.775ml the withdrawal would kick in. But I am stubborn and I did not want this drug in my system and so I kept trying. And failing.

In 2008 I was found to have osteoporosis, a side effect of Seroxat as noted in the patient literature. At no time was this raised with me or acknowledged by my GP. In 2009 I developed a disabling 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. In 2012 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.

Prior to the onset of the movement disorder, I was strong, fit and healthy (as long as I took my 1.78ml of Seroxat daily). I had been doing yoga for 20 years, I cycled and walked miles, I went to the gym twice a week and I could leg press my own weight in kilos. I had retrained as a therapist and was in the process of building my business. All that came to an end. Movement set off my movement disorder so I became sedentary.

I stopped taking Alendronic Acid on David's advice straight away in the hope that there might be some improvement in my condition. When nothing changed it became obvious that I had to stop taking Seroxat. Getting the drug out of my system, whatever the consequences, was the only option left to letting my body and nervous system heal in the desperate hope that the movement disorder might stop. I took my last dose of 1.78ml on March 16, 2013. (Five years to the day from me sending you this submission!) These were the consequences for the next four years:

- Frequent episodes of uncontrollable muscular jerking (daily in the first year)
- Frequent uncontrollable weeping
- Daily waves of terror
- Daily nausea and diarrhoea
- Intense pressure in head as if skull being crushed
- Tinnitus
- Hyper-sensitivity to light, sound and touch
- Insomnia (around an hour's sleep a night for the first 18 months)
- Electric shocks in the head, especially at night
- Agitation (probably mild akathisia – inner restlessness, a common side effect of psychiatric medication)
- Palpitations
- Extreme weight loss (22 pounds in first 10 months)
- Persistent aching muscles and joints, muscle weakness, muscle spasms

Constant feeling of impending doom

Phobic style reactions to foods/liquids/chemicals/smells/supplements/medication

I don't really have the words to describe what this felt like to experience – our rich language seems lacking to me on this subject. There were times when I thought I couldn't bear it any more and there were times when I thought I was going mad. Fortunately, my therapy training helped me spot that I had developed a range of phobic reactions, and a friend who is a counsellor and therapist recognised that this range of symptoms is common to people who have experienced trauma. I read up on the subject and found that my symptoms did indeed fit the pattern of trauma. I went privately to see a Trauma Counsellor who diagnosed Post Traumatic Stress Injury. PTSI symptoms occur as a natural outcome (Psychiatry chooses to call it a Disorder) for people who have experienced a trauma; the Counsellor's opinion is that I went into withdrawal so many times over a period of 17 years, with each event leading to a worse withdrawal experience, that my nervous system was traumatised by the absence of the drug when I stopped for good. It was just too much to take. You can't fight or flee from a trauma happening within your own body. You are just stuck and you have to suffer.

I am left with a hyper-sensitive nervous system, I still have the movement disorder, but I am pleased to say it is much reduced, and I have a hypersensitive digestive system which prevents me from eating a number of foods or taking any supplements or medication. Whilst I can live with the fact that I can't tuck into a piece of cake, it is very difficult to be unable to take anti-inflammatories or pain killers for chronic back problems. These post-withdrawal effects of nervous system and gut sensitivities are common amongst those of us who have suffered long term withdrawal.

Question 2

What support services are available to people experiencing prescribed drug dependence and withdrawal, particularly in Wales, and whether these are sufficient?

The research I have done leads me to believe that there is only one service available in Wales which truly provides the support required to help people with PDD. This is the Prescribed Medication and Counselling Service in Mold, which is funded by the NHS and covers part of North Wales. There is no equivalent in South Wales. The Assembly government pours millions into Substance Misuse Services which do not meet the needs of someone who needs slow, targeted tapering from a prescribed drug of dependence. In my previous submissions I have commented at length on this issue. Social media and internet support sites fill the gaps. People with lived

experience of PDD are, over the internet, doing the work that trained medical professionals should be doing.

Question 3

The extent to which prescribed drug dependence and withdrawal is a recognised issue amongst health professionals and the general public.

My answer to this, simply, is it is not. This brings me to the nub of the issue as to why I raised this petition. In 1996 when I was first prescribed Seroxat and in 2000 when I registered with a Welsh GP, everyone was following the line spun by the pharmaceutical industry; that SSRI antidepressants were safe, effective and non-addictive, and corrected a chemical imbalance in the brain. Withdrawal was unrecognised, unacknowledged and withdrawal symptoms were diagnosed as a “relapse” of your original symptoms. Tapering was unheard of. Those were the circumstances that led me to where I am today.

I was shocked to discover in 2017, as I came out of my withdrawal experience, for many patients those circumstances are just the same. Even as I write this, senior people within the medical profession, people who advise governments, are bickering about the existence of withdrawal (discontinuation syndrome is the euphemism of choice) and the length of time it might last. From where I sit, this is pitiful. Those of us unlucky enough to be harmed by psychiatric medication, whether antidepressants, benzodiazepines etc., we are constantly challenged to “provide clinical evidence, not anecdotes”. The general public has just been blitzed with wide media coverage that antidepressants are safe and effective and withdrawal will last, in the vast majority of cases, for no more than two weeks. I feel very strongly that politicians have a role here to put the onus back on the psychiatrists and the GPs to provide factual evidence in support of their claims. So far, having been challenged, they are unable to do so.

It is still standard practice for withdrawal symptoms to be judged as relapse and, as a consequence, instead of safe, hand-held withdrawing, patients end up back on the drugs. For years. Just like I did. Because if you reinstate the drug when you are in withdrawal, you improve very quickly. So, QED, the drug is helping your ongoing illness. This erroneous circular logic is a key reason why there are so many people taking antidepressants; they can't get off them and they don't even realise it is because of dependency.

Question 4

Any actions that can be taken to improve the experience of those affected by prescribed drug dependence and withdrawal, including in terms of prevention, management and support.

Prevention

Harm to people can be reduced by the recognition that antidepressants, particularly SSRIs and SNRIs, cause dependence to a level equal to or greater than the benzodiazepines, anxiolytics, hypnotics and opioids. I requested in my previous submission to the Committee that antidepressants should be added by the All Medicines Strategy Group to the list of drugs that are targeted for reduction, as benzodiazepines currently are, together with new prescribing guidelines. Training is then required for the key prescribers of antidepressants (GPs and Psychiatrists).

This training should highlight the two key influencing points in the discussion between prescriber and patient when antidepressants are being considered.

1. At initial prescribing, side effects and withdrawal effects should be transparent so the patient can understand the risks and benefits and give clear and informed consent.
2. Should the patient reduce or stop their drug, and relatively quickly develop symptoms of anxiety or depression, withdrawal should be the first consideration rather than relapse. A tapering plan can then be put in place to establish what is the patient's accurate experience.

The training should also cover that evidence indicates that antidepressant medication should only be prescribed for severe depressive episodes. It should not be prescribed off-label.

It is vital that PDD is properly recognised and identified by all Welsh NHS employees. Because no-one formally accepts its existence, pharmacists, GPs, A&E departments, clinics, mental health teams etc mistakenly diagnose relapse, Medically Unexplained Symptoms (MUS) or Functional Neurological Disorders (FND) and refer on needlessly to Consultants, Specialists and Psychiatrists at a huge cost to the NHS. This causes immense additional distress to patients, particularly those who suspect withdrawal and are effectively not believed, leading to a breakdown in the doctor/patient relationship.

Management and support

GPs allot 10 minutes per consultation. This is not enough time to give the support necessary for a patient with ongoing PDD who needs close monitoring to manage their path back to health. Giving all of Wales access to an NHS funded Prescribed

Medication Support Service to match that currently provided across part of North Wales is essential. This service will even provide home visits for patients in distress with withdrawal. A service specifically targeted for patients with PDD is required because the promoted alternative is the Substance Misuse Services which treat PDD the same as street drug and alcohol withdrawal, forcing patients who have done nothing other than follow their doctor's advice to attend Substance Misuse clinics and centres. A short withdrawal for patients with PDD is dangerous and potentially life-threatening.

An NHS resource providing approved on-line access to information about PDD, including effective tapering plans for each drug is needed for patients, GPs, nurses etc. Access to an on-line chat service would be valuable, and this could tie in with the existing 24 hour CALL Helpline already available in Wales. As I mentioned earlier, patients resort to the many websites and social media groups set up worldwide to fill the gap, and peer experience is the main source of information and support. I must stress here that I had no formal tapering guidance, I used the internet as my source and I fundamentally misunderstood how to manage my tapering and what to expect. This led to me being on Seroxat for far longer than I should have. In a separate document as an Appendix to this submission, I am providing a list of the range of on-line resources for antidepressants and benzodiazepines that people currently use – it is a mere snapshot.

My final comment is to urge the Welsh Assembly government to listen to people with lived experience of PDD who are the true experts on this subject, and include us in the development of strategies to help people who are struggling. Our only vested interest is to ensure that others do not suffer in the way we have. As I was preparing this document to send to you, I read that in England 67.5 prescriptions for antidepressants were written in 2017, an increase of 3 million. The Royal Colleges of Psychiatrists and GPs will claim in the media this is good news. I beg you to consider that it is not.

W2 – By Anonymous

1. Experience of Prescribed Drug Dependence and withdrawal:

This document was first written for the Parliamentary Group on drug misuse, 10 years ago, at the suggestion of the BAT group (Battle against Tranquillisers) in Bristol in 2007. I was the carer and supporter of my wife (UM) (aged 71 at the time of writing this doc) who has suffered extremely unpleasant, painful and debilitating

symptoms of prescribed drug (Lorazepam) dependence, and latterly withdrawing from Lorazepam, and then Diazepam, between 2005 and 2007.

It is demoralising that the Welsh Government are still at the stage of consultation “petitions committees” and “calls for evidence”, after I, and no doubt so many others, shared our experiences with this UK parliamentary group on DD, including detailed suggestions of what needs to happen, over a decade ago!

Support services: there were no support services in Wales available in the mid 1990s, when UM was first experiencing prescribed drug dependence and withdrawal. Indeed even by the mid 1990s, the primary care medical service – her local GP – were unaware of the existence of prescribed tranquiliser dependency.

In this summary I have included in bold the English and overseas support services – and information – that I found, through desperate research:

- 1. Council For Prescribed Tranquiliser Addiction: Founder Pam Sharples “Back to Life” booklet 2003 Followed by meeting and telephone consultations 2004.**
- 2. Battle Against Tranquilisers: support meetings weekly in Britol 2003. Una Corbett**
- 3. “Breaking your Prescribed Addiction” book by Billie Jay Sahley of The San Antonio San Antonio Pain and stress center Texas USA. Followed by phone consultations 2007&8.**
- 4. “Benzodiazepines and how they work” 2002, by Professor C Heather Ashton, DM, FRCP University of Newcastle.**

2. Experience of Prescribed Drug Dependence

In 1972, aged 36 my wife (UM) was prescribed Equagesic for sciatica and back pain “as needed” and shortly afterwards Ativan (Lorazepam) on the same “as required” basis for distressing Tinnitus (probably, in retrospect, caused by the Equagesic). She took both these drugs on occasion and as directed for many years, until Equagesic was withdrawn in 2002.

UM did express her concern to her GP in the early years about taking these medications, and was told in reply, “did she want to have back pain or not?” which

gave her the impression there was no other choice available to her to manage the pain.

UM took 0.5mg (1 / 2 of 1 pill) as required to relieve these symptom, on and off for many years.

By the mid 1990s, with UM suffering increasing frequency and worsening of back pain, tinnitus, increasing anxiety, changes in her mood to the extent that she “just didn’t seem herself anymore”, I asked her GP if there was any chance that these developments could be due to the Ativan prescription. I was told unequivocally no, not in any way could Ativan be the cause.

None the less, unhappy to be taking the Ativan, UM tried to reduce the Ativan dose throughout the 1990s, without any medical assistance or psychological support, as it wasn’t recognised as a need, none was available and her GP did not believe it was causing the problems.

UM occasionally increased the dose from 0.5 to 1.5 mgs Ativan in times of great stress 1990–1991, 1997–1999.

By 2003, worsening symptoms of tinnitus and anxiety, and by now exacerbated by panic attacks, severe feeling of going mad, retching and churning of the stomach, severe fatigue and morning misery had pushed her to the edge of despair. UM increased the dose of Ativan from 0.5mg to 1 mg per day to try and control these worsening symptoms: and perceived her situation as hopeless. She was a different person when the symptoms subsided, but for much of the time was under their iron grasp.

We enlisted the help of a private psychiatrist to help UM cope with this harrowing situation.

I came across “**CITA (Council for Involuntary Tranquiliser Addiction, later named Council for Information on Tranquilisers and Antidepressants) booklet “back to life”**. Based in Liverpool and founded by ex Nurse Pam Armstrong Sharples who had witnessed huge distress of patients on prescribed tranquilisers, CITA was endeavouring to bring knowledge and relief – through sharing information and tapering practices with doctors and sufferers. (Documents A)

3. Experience of Prescribed Drug Withdrawal

Thanks to the "Back to Life booklet", we now understood UM's issue was prescribed tranquiliser dependency. In 2003, armed with this information, her GP and the psychiatrist we had contacted to help UM, tried to wean UM off Ativan and onto equivalent dose of Diazepam.

This didn't work. From the start UM quickly felt totally disorientated, muzzy headed and was terrified of both sensations, anxiety increased.

Diazepam was withdrawn and UM decided to come off Ativan instead by physically breaking tablets into smaller and smaller bits over a period of time. This was done with her G.Ps knowledge.

After a period of prolonged self administered withdrawal over 13 months, UM successfully came off Ativan in December 2004, albeit suffering a variety of severe withdrawal symptoms, the worst of which were – Frequent bouts of random and sometimes intense pain, Frequent (every 2–10 days) Nausea, Panic attacks, Tinnitus and Migraines plus many other minor irritants.

Frequent attacks of Migraine and returning back pain in Feb/Mar 2005 prompted a return to Ativan with the knowledge of her GP, which was followed in the summer by severe Nausea and Pain and then followed by a transference from Lorazepam to Diazepam (2 mg per day) and further gradual reduction.

By the summer of 2006 Diazepam had been reduced to ½ milligram per day when a further period of intense pain required a tripling of the dose to obtain relief.

This was again followed by a withdrawal procedure (with the assistance of BAT) until the summer of 2007 when the same pain recurred and was again relieved by the same dosage increase followed by a similar withdrawal pattern.

At the present time she is taking just over 1 milligram per day of Diazepam.

This whole process has been most demoralising as well as debilitating as some of the withdrawal side effects have been present much of the time and totally disruptive of anything approaching a normal standard of life.

In 2007 UM underwent the withdrawal regime as inspired by the writings of Billie J.Sahley from the *San Antonio Pain and stress center Texas USA*.

UM was never again able to withdraw from the Ativan dose, and continued to suffer and bear the increasing effects of tranquiliser withdrawal until her stroke in November 2013. Through the same sheer grit and determination to overcome the tranquiliser dependence, UM recovered from the stroke, though has needed 24/7 care since and continued to suffer.

During a period in hospital in 2016, her consultant succeeded in reducing her Ativan dose to 0.25mg per day. This seems sustainable but has UM in an almost permanent state of withdrawal and she is prone to intense back spasm, headaches, bladder spasm, nausea, tinnitus.

UM survived Hospital acquired pneumonia in 2018 and is now in a care home. Her complex care needs meant she recently underwent a CHC assessment. She is still on 0.25mgs of Ativan, and still suffers. Her Ward failed to see the evidence of this as related to Ativan. The recently qualified doctor in the meeting denied the ability of .25mgs of Ativan to cause any withdrawal symptoms at all. And so the misinformation and lack of understanding continues.

UM continues to be the most courageous woman I have ever met.

4. Actions that can be taken to prevent prescribed drug dependence occurring. What needs to be done.

- A. Establish the extent of the problem by
 - 1) Making doctors record every prescription for Benzodiazepines (and dosage)
 - 2) Making every prescription for Benzos. over 14 days compulsorily notifiable to APPGDM
 - 3) For any patient prescribed Benzos in excess of 3 months, record the reason for all GP consultations (to identify likely side effects). In this context I suspect that a huge amount of NHS resources are expended trying to treat, unsuccessfully, the symptoms of side effects of Benzo prescription. In my wife's case this included numerous GP visits, some X-rays, psychiatric services and an CT scan.

- B. Make the booklet 'Breaking your prescribed addiction ' by Billie Jay Sahley or at least the knowledge contained in it a compulsory part of the curriculum for Medical students, and recommended reading for all GPs, qualified Psychiatrists , Psychologists and anyone concerned with Benzo usage (and drug related welfare in general).

- C. Consider the role of the pharmaceutical industry developing new patentable medicines (I understand that substances naturally occurring in the human body are not currently patentable and therefore the industry has to find new - and possibly dangerous - substances which can be patented in order to make their profits). Maybe making the application of (or combination of)

natural substances more easily patentable would encourage research into natural products and a more natural approach.

- D. Consider the role of the pharmaceutical industry in 'cleaning up the mess' it has created with Benzos (and probably will with SSRIs as well).
Lead legal group actions against Roche and the other manufacturers of Benzos to force liability for failure to test for sufficiently long time to understand the long term dependency effects of these drugs. Use the fines to finance 2 x clinics set up in Wales, 1 in Northern Ireland and 3 in England along the lines of the San Antonio Pain and Stress centre which works through outreach telephone helplines and clinics to help ease the withdrawal from Benzos.
Make a proportion of Pharma' industry profits go to the maintenance of these clinics in perpetuity.
- E. Education, Having established the extent of the problem consider –:
Prominent health warnings in general (as for tobacco) and ensuring every Benzo prescription comes with a specific health warning, Widespread publicity, T.V. and press (paid for by the manufacturers), establish counselling personnel (or access to) in every GP practice (or maybe a group of practices could combine facilities depending on the extent of the problem).
- F. Research how the various patient personality categories react to the various drugs. (e.g. If only Type A personalities suffer adverse drug , or drug withdrawal reactions, don't prescribe them to Type A patients)

I suspect that there is a huge amount of POM induced misery, which often goes unrecognised and undiagnosed, out in the population at large and this needs to be assessed and addressed. As my experience is only of POM, I cannot comment on OTC medicines or the much better publicised effects of recreational drugs.

So an opportunity exists for government sponsored university research which could produce massive savings in terms of substantially reducing over-stretched NHS resources and, in the wider field, of reducing the expense of drug related crime, particularly in the light of the recent trend of combination drug usage involving Benzos.

W3 – By Anonymous

i am a 44 yr old male and i was diagnosed with depression/anxiety and was given an ssri to help.

the dr or pharmacist didnt inform me of the dangers of this drug.

in the first week i experienced severe adverse reaction i have regurgitated and dirtied myself but the dr made me continue and played around with doses.

Now i am currently disabled. Lost my family and job my house. It took me yrs to achieve all this and lost it in a week.

The science of psychiatry is based on a false reality. Chemical imbalance myth has not been proven and actually the drugs given cause the chemical imbalance. The big companies are hiding the facts. There are over 30 groups and forums online thousands are in agony. Experts like Dr. Ann Tracy Blake. Dr. Peter Breggin Dr. David Healy Dr. Peter Goetze have been collecting data and have been battling against the big pharma companies. The crime rates are increasing. In every mass murder ssris are involved. The population the public are being hurt by these drugs and yet they are still available. These drugs are costing governments bc whoever uses it will develop other severe illnesses such as diabetes or heart disease or in extreme cases lose jobs. Will have to live on disability and welfare.

There is a silent genocide and secret epidemic going on. Please listen to the experts please listen to our cries. Please stop these big companies from poisoning us.

Please help us. These SSRIs are devils work these drugs are purely toxic. The science of psychiatry is fake. they are unintentionally poisoning people. They must be stopped. These drugs they are highly addictive and are no better than a placebo. I am ready to talk anytime. I am begging u save ur children and family from these toxins.

W4 – By Anonymous

I am writing to you in response to your request for people with lived experiences of taking and withdrawing from prescribed drugs.

I took the SSRI Seroxat for 18 years, including the 5 years it took me to come off. In that time my doses ranged from 20mg to 50mg a day. For the majority of that time I was taking 30mg. At first I found the drug to be useful as it reduced my anxiety and stopped me from suffering from panic attacks. However, it also stopped me from feeling anything at all, I was emotionally numb. They changed my personality and made me act in ways I feel I wouldn't have had I not taken them. Without the ability to feel empathy or guilt I unfortunately upset and lost friends through my behaviour. They increased my cravings for alcohol which made my behaviour worse,

and I've narrowly escaped a serious drink problem by coming off them. They had no effect on my depression, in fact over time the lack of feelings became a cause of depression in itself. They left me with no libido and erectile dysfunction. This affected my relationships and made me shy away from potential ones. The impact of this left me feeling increasing suicidal, lonely and more depressed.

After my father died I was unable to grieve, and 12 months later I became a father myself. I knew at this point I needed to come off the drug in order to be emotionally present for my daughter. From previous half-hearted attempts at coming off I knew I would be unable to hold down a job whilst withdrawing so decided to go to university. Due to having had previous failed attempts at coming off Seroxat my GP referred me to a psychiatrist. Her advice was to swap from Seroxat to Prozac. I tried this, but by day 3 I was suffering from electric shock sensations throughout my body, headaches, nausea, hot and cold flushes, anxiety, extreme agitation, pins and needles, bursting into tears one minute and extremely angry the next. On the fourth day I presented myself at A&E. Apart from feeling I was about to have a heart attack, my anger and agitation had escalated to a point I didn't think was humanly possible. I feared I was going to kill myself and my family. I was given a course of Valium and put straight back on Seroxat.

I was referred to a prescribed medication dependency counsellor where a slow taper regime was put in place and I was prescribed the liquid version of my medication to enable me to reduce by very small amounts. However, even this became too difficult by the final year of my degree as I was unable to concentrate. I had to reinstate my full dose and wait until I'd finished university.

Once I completed my degree I was signed off onto sickness benefits in order to make another attempt to come off. This time I did come off Seroxat successfully using a very slow taper over 2 years. However, even this protracted withdrawal was difficult and I often had to resort to Valium and sleeping tablets to manage my symptoms. In fact my psychiatrist made the decision to put me on sleeping tablets permanently knowing that I would become addicted to them. Once I was off Seroxat it took me a further few months to withdrawal from the sleeping tablets. None of this would've been possible had I not had the support of the drugs counsellor, these services were essential to me.

Although I had no craving for Seroxat whilst withdrawing, I did crave alcohol, Valium and sleeping tablets due to the rapid relief they'd offer me from the withdrawal symptoms. It is because of this I would consider antidepressants to be an addictive drug.

I have now been free of Seroxat for three and a half years. I still feel emotionally numb, I'm in a permanent state of depersonalisation, I still have a low libido, and am taking the highest dose of medication for erectile dysfunction with only limited success. I feel more deeply and chronically depressed and suicidal than I did before I took the medication and I believe this is due to the lasting effects of the medication itself and the damage it has done.

In terms of support I feel I was very lucky to come off the drug when I did. Since then there have been severe cuts to mental health services, especially in psychological therapies. I can't express how vital these services were to me. I was lucky to find a GP in my practice that was sympathetic and understanding of the issues I faced. Many GP's I saw were poorly informed about SSRI withdrawal. They need to start listening to what patients are telling them, not what it says in their books. Having the services of a prescribed medication dependency counsellor was vital, as few others within the NHS took the severity of my withdrawal symptoms seriously. I was also attending a psychodynamic therapy group for the duration of my withdrawal period, having that support was also hugely important to me.

Although I am happy for the content of my letter to be published, due to the sensitive and deeply personal nature of what I have revealed, and the extreme suicidal distress this causes me, I wish to remain anonymous.

W5 – By Diane Dunsmuir

Dear Mr. David Rowlands, Chair of Petitions Committee,
Thank you for hearing our stories. I live in the United States and I have been harmed by both a Benzodiazepine and a SSRI. My story is unique, in that I had an adverse reaction to both medications. I later found out that due to my DNA, I don't metabolize a number of medications properly, so what turned out to be a medication induced problem led to more and more medication, thus causing more harm. The worst harm was having to endure horrible withdrawal symptoms for years in trying to get off of the very medication that was already toxic to my body.

I started having tremors of my hand and neck in December of 2015. At this time I had been taking medication for allergies. Being new to Texas, I had not experienced allergy symptoms before, especially not during the winter months. I was prescribed Propranolol for the tremor and the following day seizures, tremor, and moments of mutism ensued. During my hospital stay I was on benzodiazepines and seizure medications. I had many tests from a spinal tap, EEGs, MRIs, and even a brain biopsy to rule out an issue with a lesion they had found. My benzodiazepine dose

varied with IV Diazepam and Lorazepam and PRN Lorazepam pills for symptoms, which at times accumulated to over 5 MGs a day. My symptoms worsened during my stay to include dysfluency, expressive aphasia, sensory overstimulation to light and sound, neuromotor dysfunction, slowed cognition, hypersomnia, my tremor became hyperkinetic and my seizures continued. My last day at the hospital they discontinued the benzodiazepines and, unbeknownst to me and my medical professionals, that was my first experience with withdrawal syndrome.

Because my seizures, later found to be non-epileptic physiological seizures, did not show up on the EEGs, I was diagnosed with anxiety. The doctors continued my prescription for Lorazepam 3 MG a day and I left the hospital in worse condition than I had come. My doctor instructed me to wean off of Lorazepam by .25 MG by cutting my pills in quarters. Each time I tapered my dose I had an increase in symptoms. She added a prescription of 20 MG of Paroxetine to help me to taper from the Lorazepam. When that didn't work, I remained on both, both my doctors and I believing that I needed the medication.

The addition of Paroxetine worsened my sedation and was causing head drop moments that I had attributed to seizures, but were later diagnosed as extreme sedation. My physical therapist had also seen signs of spasticity and clonus. My symptoms continued to worsen as I saw doctor after doctor. My neuropsychologist performed testing that showed that I did not have an anxiety disorder but had many other cognitive impairments in addition to the neuromotor dysfunction.

I ended up in the hospital again as my symptoms worsened and during that hospital stay my doctor removed my Lorazepam prescription without consult. I went into cold-turkey withdrawal, which caused severe oromandibular and torticollis dystonia and a major increase in seizures. My face would distort when I tried to eat, drink, or talk, and my neck curled up tightly to my shoulder causing me to seize. My tongue curled up in my mouth causing me to suffocate myself and I had no idea why. If I had been discharged that day as originally planned I may have died.

My husband contacted my doctor and they gave me a rescue dose of .50 MG Lorazepam. That night my other symptoms calmed but I was sweating profusely, my anxiety was high and my thoughts raced from one nonsensical thought and image to another, I had nausea, my head was pounding, I had random pains throughout my body, and my heart was racing. I still couldn't eat or drink and I could not sleep.

Finally that morning I was able to get a little nap and when I woke up I felt better, not just better from the night before, but better from the eight months since I had

been on Lorazepam. The team of doctors came in and one of the doctors mentioned he had taken me off of Lorazepam and he was scolded by his superior. Because my diagnosis remained anxiety I was to be discharged, so instead of getting to the root of the problem, they reinstated my prescription at a lower dose of 1 MG a day and sent me home with instructions to taper off of both drugs.

I found a psychiatrist to help me taper off of the medications, but though I told her about my problems tapering in the past, she continued with the same recommendation of .25 MG tapers and just as before, my seizures and other symptoms, which had been gone since the cold-turkey withdrawal, started back up again.

When I visited my primary care doctor after all of this he performed the DNA test that showed that I rapidly and ultra rapidly metabolize many drugs and that caused the adverse reactions I had from the beginning. Since he had a better understanding of what had happened he helped me taper off of the medications, offering some guidance, but mostly letting me do what worked for me. He prescribed me liquid compounds to help make the process easier.

Withdrawal symptoms were difficult. Though I no longer had seizures, I still had many disabling symptoms. Following my May, 2016 cold-turkey experience, I had the following withdrawal symptoms, which varied at different times, for almost two years:

Agitation	Headaches and migraines
Misperceived threats	Adrenaline surges
Irrational rage	Frequent infections
Anxiety	Inflammation
Panic attacks	TMJ (temporomandibular joint dysfunction)
Brain fog	Heartburn
Memory loss	Nausea
Confusion and disorientation	GERD
Crying spells	Extreme fatigue
Sensory overstimulation	lethargy
Problems with concentration, planning, organizing, and math	Adrenal insufficiency
Neuromotor dysfunction and discoordination	Nerve jolts
Muscle pain	Restless legs
Joint pain	Myoclonus during sleep and upon waking
Muscle contractions	Heart palpitations
Motor jerks and spasms	Chest pain and tightness

Night sweats	Problems with speech and memory retrieval
Hot flashes (not yet menopause age)	Internal vibrations
Tremor (no longer hyperkinetic)	Scalp pains
Tinnitus	No libido
Head pressure	Problems with vision
Weight gain	Eye twitches
Unable to make decisions or multitask	Vivid or intense dreams and nightmares
Insomnia	

My doctor and I decided to try to switch me from Lorazepam to Librium in May of 2017 since Librium is a drug that I should metabolize better. My doctor instructed me to take both Librium and Lorazepam for two days and then stop taking the Lorazepam. My first dose adding the Librium left me completely sedated. I decided not to continue with the switch. That one added dose caused me to be kindled. Once I was kindled my symptoms magnified and since, I have frequent brain fatigue and overstimulation which causes a cognitive slow down that affects both thought and speech.

I have been off of Lorazepam since the last week of December 2017 and yesterday I took my last dose of Paroxetine. The brain fatigue and overstimulation, though improved since I was first kindled, continues to this day. I am limited to what I can do and I have to take frequent rests and naps. My memory has improved much since I came off of the benzodiazepine but it is still impaired. The GERD symptoms reappear at different times, usually in response to trigger, such as a glass of lemonade or a beverage or vitamin that contains propylene or ethylene glycol.

I have not worked in over two years. I had a wonderful career that I loved, working as an activity director in a nursing home. I can no longer supervise a group of people and I no longer have the stamina to work at something for more than a couple of hours at a time, less if it requires cognitive ability. I have yet to see how much of my symptoms will be protracted now that I have finished with the medications.

If my doctors were more informed about withdrawal syndrome my experience would have been far different. My doctors would have instructed me to reduce at a slower rate and allowed me to determine, based on my symptoms, how slow I needed to go. I would never have had an addition of a SSRI, which not only worsened my symptoms, but substantially added to withdrawal time and suffering. I wouldn't have been kindled, because my doctors would have known better than to increase my dose. I wouldn't have the prolonged cognitive impairments that still affect me

today. I would still be working at the job I loved and I would have been able to care for my spouse and child, instead of having them caring for me.

I had no doctors that understood or even informed me about withdrawal syndrome. All of my information came from many antidepressant and benzodiazepine withdrawal online and Facebook support groups. My primary care doctor was the only one who listened and allowed me to do what was best for my body. Only one doctor of my team, of several, at Yale understood the effects of a cold-turkey benzodiazepine withdrawal. Prescribed polydrug effects were not considered when my doctor added the SSRI to help with withdrawal. I now know that there are no drugs that help with withdrawal.

Firstly, I believe it should be the doctor's and pharmacist's duty to inform us about the potential for withdrawal syndrome and allow for our consent before treatment. According to the prescribing information, benzodiazepines should only be used for two to four weeks. It should be the patient's right and responsibility to determine if they want to choose this drug or continue this drug past the recommended four weeks with the knowledge that there is a potential risk of withdrawal effects. Doctors and pharmacists should fully understand benzodiazepine and antidepressant withdrawal to assist us in coming off the drugs slowly, referencing *The Ashton Manual*, by Dr. Heather Ashton, to help us to avoid severe discontinuation symptoms. They should also understand that each person is unique and their symptoms may vary based on their individual DNA and metabolism rate. Doctors and pharmacists should be aware of the potential for unforeseen polydrug effects, and doctors should provide regular follow-up appointments with the patient in the event they need more than one psychotropic drug. Doctors and pharmacists should also be aware of the potential for a kindling effect, informing the patient before they start their prescription about the risks of up dosing and the importance of maintaining their dose. Patients should be warned prior to prescription about the potential for severe prolonged and protracted symptoms if the patient abruptly discontinues their medication. Patients should also be made aware of the potential for long term cognitive damage from these drugs and the increased risk for dementia. Women of childbearing age should be warned that they should avoid pregnancy on these medications and that according to research, they do pass through the utero barrier to the fetus ("All psychiatric medications cross the placenta and reach the developing fetus," Harvard Health Publishing, December 2008). The elderly are at much more risk for symptoms, falls, and even death. The use by our elders should be avoided (*Today's Geriatric Medicine*, Jamie Santa Cruz, 2017).

It would also be beneficial for an online service, like the support groups, but with trained medical professionals that provide medical information and solutions to symptoms, instead of people like myself, who are just figuring things out as they go along. This can offer guidance for those unable to seek help from a doctor. The support groups are great, but there is as much bad information and advice on them as there is good.

Knowledge is the best prevention. If only every doctor I had seen had been informed, and I saw many epileptologists, neurologists, psychiatrists, psychologists, general practitioners, and rehab specialists. If they were knowledgeable and were required to provide this information to their patient, I would not have lost over two years of my life.

I hope you make change, not only for the thousands of us that are suffering now, but for the hundreds of thousands that are currently on prescriptions, ignorant and unaware. This issue is as big as the current opioid crisis and the time for change has come.

W6 – By James Moore

1. Your experience of prescribed drug dependence and withdrawal.

My name is James Moore, I live in South Wales and have been struggling with withdrawal from an antidepressant (Mirtazapine) for just over 11 months now. I have been taking my antidepressant for five years and I expect, given the severity of withdrawal symptoms, that it will take me another year to stop the drugs completely.

If I try to withdraw too quickly, within a day or two I become bedridden and unable to function with blinding headaches, nausea, tremors, dizziness, restless, anxiety and agitation. My original diagnosis was depressive illness with none of these effects being a part of my diagnosis, they have only occurred since I started to withdraw. I am unable to work and housebound. Withdrawal is the single most gruelling and challenging experience of my life and I know that I am far from alone. I understand what is happening to me, many don't and are frightened by it.

I am fortunate to have a supportive local GP who is allowing me to withdraw using a liquid which allows for more precise tapering than is possible by pill cutting. I know that many are not so fortunate and their doctors do not understand or, even worse, given them poor advice to stop quickly. The NICE Guidelines¹ that doctors consult are clear that people should withdraw slowly over at least 4 weeks, however,

doctors often recommend other methods (such as taking pills every other day) which are not evidence-based. Typically, this will result in significant withdrawal effects which ultimately end up misdiagnosed as relapse and the patient will go back on the drugs or increase dosage as a result. As Dr. David Healy, psychopharmacologist at Bangor University notes, this is part of the reason for the escalating antidepressant prescription numbers in Wales, it is part new prescriptions and part dependent patients who are unable to stop.

2. What support services are available to people experiencing prescribed drug dependence and withdrawal, particularly in Wales, and whether these are sufficient?

There are no dedicated services in South Wales that I am aware of. There are substance misuse resources, but these are not suitable when dealing with the complexities involved with prescribed drug dependence. It is also demeaning to lump together substance misusers with those who followed their doctors advice to the letter.

I personally have called NHS 111 who could offer no advice but to go and see my GP. My GP is understanding but her time is limited, she cannot possibly make the time available to give me the kind of support that I need so, like many others, I self support and rely on online resources to fill the alarming gap in skills, knowledge and experience amongst medical professionals.

Services, as they stand, are utterly insufficient, in my view, to deal with a potentially very large public health issue. In Wales, 1 in 10 are on antidepressants (confirmed in Dr David Healy's letter of 23rd November 2017), some 300,000 people. If 55% of those struggle to stop (see below) that is 165,000 people in need of advice and support and a significant demand on already stretched GPs.

3. The extent to which prescribed drug dependence and withdrawal is a recognised issue amongst health professionals and the general public.

I will not mince my words here, please forgive me. The medical profession is in complete denial about withdrawal effects and seeks to downplay the severity and longevity of withdrawal because they have no answer to the problem. The largest ever study on this was undertaken in 2017 by Professor John Read and colleagues (I believe that Professor Read has also written you). In a survey of 1,829 New Zealand adults taking antidepressants, 55% reported withdrawal effects. 25% of the 1,829 described their withdrawal as 'severe' 17% 'moderate' and 12% 'mild'. Most worryingly, only 1% recalled ever being told about the possibility of withdrawal when the drugs were prescribed.

Doctor David Healy will also similarly confirm that more than half of those taking an antidepressant for more than six months will have problems stopping the drugs.

You may well have experts who will insist to you that withdrawal is a minority experience or that the symptoms are 'mild and self-limiting', I beg you to ask them for evidence that proves that statement to be true. They must have based that statement on studies of withdrawal, so for the sake of clarity and openness, let's see that evidence. If they don't know, why don't they know? Antidepressants are the single largest class of psychiatric drug prescribed, to not know how many struggle coming off the drugs is an alarming gap in our knowledge that needs urgent action to rectify. Whether antidepressants help lift depressive states or not, withdrawal is a major challenge for a significant number of people.

4. Any actions that can be taken to improve the experience of those affected by prescribed drug dependence and withdrawal, including in terms of prevention, management and support.

There are a number of actions that we should consider:

- Provide specific, evidence-based guidance on withdrawing from psychotropic medications to support GPs and assist them in having withdrawal discussions with their patients.
- Give pharmacists a greater role in supporting users with better information and guidance specifically for those withdrawing.
- When a psychotropic drug has been prescribed, a formal review meeting should be arranged at eight weeks, if the patient shows no improvement, the presumption should be that drug treatment stops unless there is compelling medical evidence to continue.
- Provide better training and updated NICE Pathways guidance for GPs on the benefits versus risks of psychotropic medications to allow patients to make an informed choice about treatment.
- Patient Information Leaflets (PILs) should be updated to include information on stopping your medication and how best to avoid withdrawal problems.
- Set up high quality, randomised controlled trials to provide evidence of the best way to withdraw from a particular drug, including tapering rates and ways to minimise symptoms.
- Provide an online portal where users can get accurate information on stopping or reducing prescription medications with online chat access to health professionals (GP/psychiatrist/pharmacologist).
- Set up an official forum for users seeking support, perhaps moderated by healthcare professionals and that includes lived experience input.

- Create dedicated user groups that can use real experiences as a basis for future action/investigation.
- Keep a central database of drug withdrawal effects for reference and future study, encourage reporting of withdrawal effects via the MHRA yellow card scheme.
- Dedicated helplines should be provided and these should be funded by pharmaceutical manufacturers rather than from the public purse, we use their products, they should be supporting and advising on these issues.

1. NICE Pathways Guidance:

pathways.nice.org.uk/pathways/depression/antidepressant-treatment-in-adults.pdf

10 Stopping or reducing antidepressants

Advise people that discontinuation symptoms¹ may occur on stopping, missing doses or, occasionally, reducing the dose of the drug. Explain that these are usually mild and self-limiting over about 1 week, but can be severe, particularly if the drug is stopped abruptly.

Normally, gradually reduce the dose over 4 weeks (this is not necessary with fluoxetine). Reduce the dose over longer periods for drugs with a shorter half-life (for example, paroxetine and venlafaxine).

Advise the person to see their practitioner if they experience significant discontinuation symptoms. If symptoms occur:

- monitor them and reassure the person if symptoms are mild
- consider reintroducing the original antidepressant at the dose that was effective (or another antidepressant with a longer half-life from the same class) if symptoms are severe, and reduce the dose gradually while monitoring symptoms.

W7 – By Anonymous

I was prescribed Prozac and took this medication for nearly 25 years. I recall that it was prescribed when I went to see my GP because I was suffering constant tiredness, he told me this was depression. I don't believe I ever suffered depression until I was took Prozac. I do not recall any of the doctors I saw during those 20+ years that I was prescribed this medication ever discussing with me any problems I might have if I took it long term or talking to me about how I could taper off the medication, or symptoms of withdrawal. There were a few times during this 20+ year period that I stopped taking the Prozac, each time within a week I dropped into a "big black hole" and was unable to function. I was sufficiently frightened that I reinstated and did not try to stop taking them again for some years. I therefore have to conclude that I had become dependent on Prozac.

During the years I have taken Prozac I have suffered with depression, anxiety and panic attacks. In latter years I have felt generally so unwell I made the decision that I needed to come off the medication. I used the internet to find out that I would need to taper off and how I could support my body during this process with a healthy diet and lifestyle. When I approached my GP she agreed that I should taper the medication, but at a much faster rate than I anticipated from what I had read. When I asked my GP what support there was available to me whilst I went through this process she told me that seeing a GP was the only support available.

I tapered as advised from this medication and took the last dose 19 months ago. I have been suffering various withdrawal symptoms during this time, most of my symptoms began about 4 months after I finished tapering and continue to evolve. The following is a list of some of the symptoms that I have been suffering during this time:

- Anhedonia (inability to feel pleasure in normally pleasurable activities)
- Extreme anger
- Obsessive thoughts, compulsive behaviour
- Making plans for suicide
- Brain fog, poor concentration, no ability to make new memories, confusion
- Lack of motivation or purpose
- Social anxiety, reclusiveness, inability to interact socially
- Inability to cope with emotions
- Hypersensitivity to stress, noise & adrenaline
- Inability to cope with emotions
- Hypersensitivity to stress, noise & adrenaline
- Constant pain throughout my body; back hips, shoulders, arms, hands
- PSSD (Post-SSRI Sexual Dysfunction)
- Digestive issues and food sensitivities
- Inner shakiness, feeling of being off balance

When I have approached my GP and told her I am suffering from withdrawal symptoms she has not acknowledged this or indicated that she has any knowledge or willingness to discuss withdrawal symptoms, instead she has suggested that it's my age and perhaps I am menopausal. Whilst going through withdrawal I have been almost unable to work and have had to leave my job due to my cognitive impairment and because the levels of pain I was suffering from working became intolerable. I have no idea if these symptoms will ever improve or if they will continue to worsen. I have completely lost my confidence and have no idea if I will be able to work and support myself in the future. I have nobody I can discuss any of this with and I am really shocked that there is no support or information whatsoever available to people in my position. After much persistence and a wait of a year I

have finally been offered an appointment to be assessed for counselling; I got this referral not for antidepressant withdrawal but for social isolation.

I don't believe I will ever again be the productive, happy, sociable person I used to be because of one 10 minute appointment where a GP decided it was appropriate to prescribe me SSRIs with no warning of possible side effects. I believe that it is vital that advice and support is available to those who wish to stop taking prescription drugs should have a much greater awareness and understanding of the problems of withdrawal. I think it is very important, especially with the large increase in prescription of antidepressants, that there is expert help and support available to all those who are coming off these medications and suffering the effects of withdrawal.

W8 – By Kim Marriott

I have been prescribed many drugs over the years since having psychosis at the age of twenty. Some of these drugs sedated me so severely I could hardly walk. I tried a variety of combinations over four decades all with limited effect. I have tried many antidepressants including tricyclics and SSRIs. About 10yrs ago I was prescribed an snri – venlafaxine, for almost 2yrs then the consultant wanted to try me on another drug instead of venlafaxine and instructed me to stop. I went through horrendous withdrawals and was suicidal. He was very shocked by my reaction and quickly prescribed me duloxetine also a snri. It helped with depression for a while but I lacked motivation and felt a bit numb. 3 yrs ago I felt duloxetine had become ineffective and so I started slowly reducing it over a period of three months. I had a difficult time with stomach problems, dizziness, headaches, insomnia and anger. I hoped to speak to my consultant about a new treatment but the withdrawal symptoms of duloxetine were so frightening I re-instated it. I had become addicted to them. I had to increase the dose also as the original dose was ineffective. Like before they have become ineffective recently but I am afraid of withdrawing. I have short term memory problems, dizziness and stomach problems which I put down to duloxetine. I am hoping my consultant will support me to withdraw eventually. I feel my only hope is through psychotherapy. I have been awaiting EMDR therapy for over a year now. I never thought that antidepressants could be so addictive. I have learned a hard lesson.

In a second email:

In addition to my previous letter. I would like to say with regard to withdrawing from antidepressants, there is no support I know of locally. I have however received information and support through some online Facebook groups. Let's talk withdrawal fb page has helped me realise that my difficulties are due to the medication I know others are going through similar. I hope to withdraw one day but I don't feel I can consider it until I am in therapy. I don't know when I will start EMDR I have waited over a year so far.

W9 – By Laura Bell

I have had anxiety from a young age but always tried my best to carry on with things. I completed school and was working. But as I got older my anxiety got worse. My problem was and what caused my anxiety was bowel issues. I was scared of needing the toilet when I went out. This led me to avoiding places and would go out at certain times when traffic wasn't bad so I could get to my destination at a quicker pace. I went to the doctor about it as I was starting to have panic attacks and now I needed some kind of talk therapy. This was never offered to me and the medication 20mg citalopram was given, I was told to take it every day. No warnings about side effects or withdrawals were given. About a year I spent on 20mg and my anxiety didn't change it was still there but I kept taking it in hope that it would work eventually. After a year had passed I went to see my doctor again and was told to increase to 40mg over that year on the 40mg my anxiety increased and got worse. I also developed a slight tremor and the panic attacks were more frequent and longer lasting. This then started to interfere with my job. I was a care worker for adults with autism and challenging behaviour. I loved my job but part of it was taking them out to do activities. I struggled continuously with panic attacks one after the other. I then could not cope and went on to night shifts so I didn't have to go out anymore.

Went back to the doctors and was swapped straight onto Sertraline/Zoloft 100mg. Nothing got better it just kept getting worse, I was dizzy all the time my migraines were constant life was a mess. I went back to the doctors and was then put on to the highest dose of 200mg. I stuck this out for another year with nothing getting better, just getting worse but I listened to the doctors that it was just my anxiety. By March 2016 I had had enough I had to quit my job I had been in for the last 8 years and my life was a mess, my body was a mess. I had constant tremor and migraines

and I had now gained another illness on top agoraphobia. I was petrified of going out of the house because I was so scared of my panic attacks by this point. I went from a girl who would have anxiety when having to go on long journeys to a girl who had panic attacks over and over again in my own home.

March 2016 I spoke to the doctor again and was swapped onto 15mg of mirtazapine. Taper schedule was only a month from 200mg of Sertraline. I began to take the Mirtazapine after about two days I started to feel very restless in my body but I kept taking them as I knew it takes a while to get into my system. After 9 days my eye sight went and my whole left side of my body went numb like I had been given anaesthetic. I thought I was having a stroke or a heart attack. After half an hour it got no better so I rang the paramedics. They came out and did a ECG and told me everything was ok but they would like me to go into hospital. I couldn't as my agoraphobia was that bad I could not leave. After a while my eye sight came back but I was still completely numb down my left side. The following morning my face was still numb but I continued to take the Mirtazapine for 5 more days. As the days continued I became more restless internally and felt very dizzy and numb. I phoned the doctor again and they told me to stop them and go on to 20mg of fluoxetine. After the very first dose I could not keep still I was pacing the house day and night in a constant panic attack, what felt like adrenaline coursing through my whole body. As the days went on it got worse and worse I was convulsing and twitching I didn't sleep for two weeks straight as every time I tried to go to sleep I would be jolted awake and would have this compulsion to pace. 14 days I lasted on the fluoxetine and I was petrified to put anymore in my body. I stopped and did not take anything after that. It has now been 10 months since this point and It has been absolute hell my body is a complete mess. I have had these symptoms constant for the whole 10 months and it doesn't seem to be getting any better:

- Constant tingling all over my body especially worst when i first wake up and when im trying to sleep. Feels like im plugged in the electric.
- Akathisia, can not sit still an electrical current running through my body 24 hours a day everyday. I pace back and four around the house as i can not keep still.
- Burning skin, like somebody is holding a match under my skin at all times. But yet my hands and feet are numb and cold.
- Bloating beyond belief
- Dizzy ness i don't no what it feels like to not feel like im on a rocking boat in the middle of the ocean.

- Itching like there are millions of bugs on my body. Sometimes it feels like they are trying to get in, sometimes it feels like they are trying to get out.
- Body jolts. Most annoying at night when im trying to sleep. Its like some annoying farmer is prodding me with a cattle prod.
- As soon as i eat it feels like my body goes into more dark places. Anxiety levels increase.
- Small amounts of food send my blood sugars up from 5.5 to anywhere between 8 and 10. Absolutely petrified to eat anything to sugary.
- Urination approximately 4 times in an hour every hour. Bladder always feels full and heavy.
- Body temperature always low.34.9 °c even though i dont feel cold.
- Clenched jaw all the time that then gives me headache. Acid/firework feeling in my head with heavy pain.
- Stabbing pains all over me
- Anxiety is on another level that i never had before.
- Crying about 20 times a day.
- Heart palpitations
- Pressure in my head like my nerves are rubbing together.
- Blood pooling in my legs and feet, when I stand up my heart rate goes to 150bpm.
 - Jump out of my skin by the slightest noise.
 - Ear pain heavy buzzing feeling constantly
 - Akathisia, pacing, shaking, twitching, cramping just pure hell and torture.

I have had no support from the medical community and just told over and over again that it is anxiety and I need medication. The medication never helped me and just made my life a complete mess. I am very ill and I'm 29 years of age I should be out there enjoying life but I'm stuck bed ridden in pain. Because I can not be still because of the Akathisia and internal restlessness I am treated like I am drugs and asked if I take drugs. My answer is NO I do not it is prescribed medication that has made me like this. I do not drink alcohol and haven't In 10 years and I do not take drugs of any kind. I can't even eat sugar now as it revs up my nervous system.

W10 - By Patricia Viney

I have been taking an antidepressant for 15 years without any supervision from my G. P.

I was not made aware of the side effects of this drug or how it would effect my daily life

Neither how difficult it would become to get off this drug.

I have currently been tapering from this drug for 2 years at a very slow pace as there is no help available for discontinuation.

Drug companies should be made to manufacture tapering packs in order to help people taper from these type of drugs when they are no longer required.

I myself have been tapering from an A.D. for 3 years at a gradual reduction as at the moment there is no help available to get off these drugs.

It is time the Welsh Government paid some attention to this matter with some urgency as it effects thousands of people.

W11 – By Shane Cooke

My name is Shane Cooke. I live in Denbighshire, North Wales.

I am 38 years of age. This is a report of the loss of over fifteen years of my life due to unknown or undisclosed problems caused by psychiatric drugs.

In 2002, I was given a prescription for the SSRI Seroxat by my GP because I was suffering from anxiety. The Seroxat caused me to have severe rage outbursts from the first few days of starting on it. I had no idea, at that point, what was causing such a massive change in my behaviour. Towards the end of the third month, following a number of visits to the local psychiatric unit, a pair of young psychiatrists decided that I should be taken off the Seroxat as it was causing many of my problems. By that time, I was hearing voices and commands and seeing alien beings etc. My usual psychiatrist agreed with their decision and decided to withdraw the Seroxat immediately, which had disastrous consequences that I will not detail here.

From those days, my life has been one long trip through a variety of medications but nothing seemed to work. The psychiatrists came up with all sorts of labels but nothing changed within me. The voices etc. were ever present and caused the level of anxiety to increase to crisis point on a fairly regular basis. My medications would be increased or changed at every psychiatric unit stay which helped for a few weeks then things would worsen again.

These times of deterioration would cause self-harming and overdosing. My family was unhappy with the lack of progress and we decided to go for a second opinion. By this time – September 2016 – I was on Quetiapine and Depakote. The Quetiapine

was prescribed as an antidepressant as all SSRIs were deemed unsuitable. Quetiapine was supposed to support in the same way and also to suppress the hallucinations. The Depakote was added as a sedative.

The 'second opinion' suggested support from a Hearing Voices Network Wales group to better understand my hallucinations, followed by reductions of the medications as I was determined to find out if reducing my medications would also lead to an improvement.

Quetiapine Withdrawal.

This is proving to be an extreme challenge in all manner of ways. I first began to reduce in January 2016. So far, I have managed to reduce from the 400mg starting point to just a shade under 150mg. The smallest dose of Quetiapine available in tablet form is 25mg but trying to reduce a full 25mg at once proved an impossible task. My psychiatrist now provides me with a liquid form which means that I can reduce in much smaller doses. The side effects in withdrawal are horrific – even at the smallest possible steps. It takes me up to three months to manage a reduction of 25mg.

During the withdrawal, I spend much of my time unable to move from my bed. I go to sleep fairly easily but cannot remain asleep. I often cannot stay in my bed for more than a couple of hours. Each day I am in fear of what that day will be like. I am unable to concentrate, cannot think straight, cannot make any decisions and simply survive by leaving my own place and going home to my parents' home. They make sure that I do eat something during the day and they take me to my many appointments. They also help to keep me safe. I am absolutely drained throughout the actual reduction and for about two weeks following. After that, each day seems to show a slight improvement – suddenly I can listen to music, another day I might be able to watch part of a DVD. Then, suddenly and without warning, everything lifts and I feel better than I have done for many years. That window of improvement spurs me on to continue with this arduous journey. This pattern of the horrors followed by improvement has already been repeated numerous times – but I know that I have to face it again, over and over.

As a result of being on Quetiapine, I have gained a tremendous amount of weight. It is very difficult to exercise enough to get rid of the extra weight due to the long spells where I am absolutely exhausted. Along the way, my physical health has

suffered as a result of being on the Quetiapine too. At the moment, my blood pressure is high and I'm on tablets to regulate that. I have lost all my teeth due to psychiatric medications – this has been confirmed by three dentists but never by a doctor. I have regular blood tests which tend to show a concern with my liver function which then calls for further blood tests. I have ECG tests – the latest showing some concern which means that I am now to see a cardiologist. There have also been concerns over my phosphorous levels.

Support in Withdrawal.

The first time that I felt some sort of control over my condition was when we went for the second opinion – and everything that I said was BELIEVED. That, in my opinion, is vital to coping with dependence and, again, in withdrawal.

Meeting with others suffering likewise – such as the Hearing Voices group – also improves the chances of coming to terms with the horrors that we suffer.

I have had sessions on Coping Strategies which are good, but when in crisis – whether in dependence or in withdrawal – all the good tips fly out of the window, such is the depth of the despair that is felt. Peer support can fill that gap. We may offer each other tips that have not yet been tried – some will work and others, with a few adjustments, can improve matters too.

The biggest problem that I have found is the fact that the service does not seem to understand that Mental Health Support is only available, at best, between the hours of 9am and 5pm on weekdays and not at all at weekends and Bank Holidays! My need for added support is far more likely to occur after 5pm and at weekends than during the available hours.

I have found a reluctance, within GP surgeries, to address the reality of drug dependence and withdrawal. They seem to shunt the problem directly onto the Community Mental Health Team – where it was my experience, prior to 2016, that they immediately assumed that the deterioration in my condition had nothing at all to do with the levels of their prescribed intervention and everything to do with my personality. In my opinion, that has to change if we are to see an improvement in provision of care and in the general public's view of the safety/dangers of prescribed drugs.

I have recently started a Prescribed Medication Withdrawal Peer Support group in our local area. I see this as my way of sharing with others the little things that have made my life worthwhile through this dark journey. Although we know that very many are prescribed the very drugs, which cause dependence and are difficult in withdrawal, in our area like in so many others throughout Wales, it is proving really difficult to attract anyone to attend our meetings. This again, I feel, would improve if only doctors could see us as a helpful source of support rather than as a group who should not be mentioned. Sweeping this massive problem under the carpet will not rid us of it. Bringing it out in the open and sharing with other sufferers is far more likely to spread the word that a better tomorrow is possible.

There has been talk lately of requesting that pharmaceutical companies cater for the tapering of their drugs in a helpful way. The problem there, as I see it, is that very few 'experts' see the full picture of tapering. Each individual MUST be allowed to taper AT THEIR OWN SPEED – a 'one size fits all' approach just will not work. Liquid forms of most drugs are available – at a price; they should be available at a nominal cost to the NHS and be widely used in withdrawal.

If all of the above were to be put in place, I feel that Wales could take its rightful place, as a wonderful home, for all its inhabitants – not just for the lucky few whose mental health has, so far, not given rise to the need for intervention from mental health services.

W12 – By Vynne Baylissa

My name is Vynne Baylissa Frederick. I am a BACP registered counsellor based in Cardiff who specialises in prescription drug withdrawal. I am writing in support of petition reference number P-05-784 and I do so with deep concern about the existing prescription drug epidemic that has created devastation and has resulted in an increasing number of people within Wales (and the rest of the United Kingdom) contacting me in desperation, due to being seriously disabled when trying to discontinue the drugs.

Background

In 1998 I was prescribed a benzodiazepine for a neurological disorder (dystonia). I had no pre-existing anxiety, depression or other psychological issues. Despite this,

I endured a lengthy, disabling and most traumatic withdrawal experience when discontinuing the drug, which rendered me housebound, bankrupt and dependent on state benefits. I subsequently recovered and have since focused on work in this area. I have delivered presentations on the subject to the British Medical Association, the Royal College of Psychiatrists, Members of Parliament and the Department of Health, as well as keynote speeches and interviews to organisations and the media including being featured in 'The Times' and 'The Independent' newspapers. My self-help book, *Recovery & Renewal*, has reached more than 15,000 readers (copies sold) and for the past twelve years I have supported more than 9,000 people affected by benzodiazepine, z-drug and antidepressant iatrogenic dependence and withdrawal, a significant number of whom reside in Wales.

My Experience with NHS Wales

I initiated my taper off the drug by taking a tapering protocol, the *Ashton Manual*, to my then GP and asking to be taken off. This resulted from doing my own research into what could be causing me to be so unwell, that it would necessitate multiple visits to my GP, many unnecessary diagnostic tests and frequent trips to the University Hospital of Wales A & E Department.

I had no input from my doctor (other than prescribing the medication required for my taper) and was left on my own to cope. I had no support whatsoever throughout my entire withdrawal which lasted from the beginning of my taper in 2003 to when I healed in 2008. I lived on my own and was isolated, misunderstood, and at one point was being coerced into having inpatient psychiatric care (which I sensibly refused) at the National Hospital for Neurology in London.

GPs Lack of Knowledge

Throughout my withdrawal experience, I was told I could not possibly be in benzodiazepine withdrawal by all the doctors I consulted. Prior to discontinuing the drug, when I told my then GP that the Rivotril was no longer effective, the dystonia was getting worse, and I would like to come off it, he replied, "Then stop taking it". This is dangerous advice that could have resulted in seizures and psychosis. Another GP told me I needed to take the drug for the rest of my life, despite my complaints of how ill it was making me feel. Later on, my then GP to whom I expressed my concerns about the withdrawal symptoms I was experiencing, told me

that I should "have a glass of wine in the evenings". After I recovered, I was told there is no record of withdrawal on my notes. Instead, my files read, "suffers from anxiety and depression", two issues I have never had. My strength and resilience saw me through to recovery.

Impact of Withdrawal

I have seen, time and again, how the withdrawal experience negatively impacts a person's life. It causes not only severe psychological and physical symptoms that often last for many months or a significant number of years, but other repercussions such as an inability to work, financial losses and debt, bankruptcy, breakdown of relationships, children being taken into care, stigmatization, isolation and suicide. The devastation that I witness daily, which includes that of individuals and families in Wales, has its origins in the lack of adherence to prescribing guidelines, unsafe withdrawal protocols, misdiagnoses of withdrawal symptoms resulting in poly-drugging, and lack of appropriate and adequate after-care for those affected, is extremely disturbing.

Sadly, there is no responsibility or accountability for the inappropriate care received by patients and the lack of support as they deal with these repercussions. There is very little understanding, knowledge and seemingly no training of doctors in this area and this has endangered the lives of patients affected by withdrawal and compromised the care they receive.

Medical Professionals affected by withdrawal

Throughout the time I have been providing support, I have had people of all backgrounds contact me, including doctors, pharmacists and nurses in Wales and, who have been blindsided by an unanticipated withdrawal experience that made them unwell and unable to work and that created chaos in their lives. However, despite promising to speak out and advocate on behalf of the community when withdrawal is over, they have chosen to remain silent, in order to not jeopardise their careers.

Impact on Economy

An often-overlooked important consequence of prescription drug withdrawal is the impact the costs of diagnostic tests and poly-drugging has on the National Health Service's budget and in your case, the NHS Wales. I know, from my experience supporting residents of Wales through withdrawal, that almost everyone at some point will have an MRI scan, an electroencephalogram, an echocardiogram, other types of scans, blood profiles and other diagnostic tests, depending on the presenting symptoms. This is usually as a result of being told their problems could not be related to drug withdrawal. Test results are normal and the patient is told the problem is psychological and they need to be medicated. They are then poly-drugged, further costing the NHS. In addition, being debilitated and disabled means being unemployable and resorting to state benefits, which is yet another avoidable economic drain.

Subsequent Problems

People who have experienced withdrawal find that even after recovery they end up receiving further inappropriate care. This is because the withdrawal experience results in a “mental health” label and any subsequent non-withdrawal health concerns raised tend to be considered anxiety-related.

Another repercussion is that people are apprehensive about speaking out. Most of the people I have supported in Wales who I have asked to write in support of this Petition have expressed concerns about being further inappropriately treated if they submit their story. Despite being reassured that this would not be the case, they have been so traumatized and stigmatized, they believe it would be too risky. As such, please be aware that the submissions you receive will not be a true reflection of the scale of this problem in Wales.

Conclusion

Serious harm is being done to tens of thousands of people, in Wales and other parts of the United Kingdom, who remain under the radar and unsupported, as they struggle to cope with the effects of prescription drug withdrawal and its repercussions. This matter needs to be urgently addressed. Please, on behalf of the many people who are suffering terribly because their lives have been devastated by this complex and cruel phenomenon, please do not contribute to the denial and sustained perpetration by turning a blind eye. Granting the requests of this Petition will save lives and reduce and prevent further harm to many. Thank you.

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