

## PE1651/DDDDD

Antón McLaughlin submission of 27 January 2018

I was prescribed Citalopram (an SSRI) for 'mild depression' in 2013, after I messed up my first year in University. Who wouldn't be in a bit of a downer after that? Regardless of context, I was labelled with 'depression' when I was compared against a questionnaire conducted by the GP. I often question after this assessment and the labelled attached to me of 'mental illness', at what point is it not normal or not simply being human to express emotion at negative life experiences? Is happiness the only acceptable emotion we should hold in ourselves, regardless of circumstances? If I had arrived in and told them my close family relative had died and I was feeling down about it for quite some time, I can guarantee I'd be told I had a mental illness.

This prescription given to me, it was the first port of call, and no counselling was offered. I had several minor reactions to starting the drug - most prominent of those was being unable to get to sleep for 2 weeks. I use to walk the streets of my town in the middle of the night just so I had something to do and to reduce my frustration. Other side effects included a stiff neck, stiff jaw, teeth chattering and inner shaking. I was reassured from my GP that these side effects would take 6 weeks to settle and it would be until then that I would see the full benefits of the drug. I remained on Citalopram for 2 years, within a month of being initially prescribed the drug a doubling of the dose was made by the GP and I remained on that dose, until one day I questioned "Why the hell am I taking this?". It served no purpose. I had no follow up or monitoring from my GP who prescribed it. It was as if they prescribed it to me indefinitely. I merely felt a former shell of myself; emotionally numb for 2 years, with no highs and no lows. What sort of life is that? Unable to feel human emotion – a chemical lobotomy. Upon inspection of what surgical lobotomy consists of, I'm horrified to read a mirrored image of what I had experienced for 2 years – marked reduction in initiative and inhibition, difficulty putting themselves in the position of others due to decreased cognition and detachment from society. Often I felt moments of confusion, and I felt brain dead, I just couldn't put my finger on words or thoughts as I was once able to. Words just didn't flow anymore. Further to this comparison of surgical lobotomy, I too developed an enormous appetite and gained considerable weight – 3 stone to be precise. My mental block and severe decline in cognitive ability woke me to the realisation that this was not natural. I was first prescribed this drug at the age of 21, I was mentally sharp and excelled in my studies. At the age of 23, I was struggling to comprehend even the simplest of concepts in my Computer Science degree and this idea filled me with dread that I may have to drop out. I worked extremely hard for my entire life in gaining that privileged position at my university of choice and I was determined to graduate. I came to the realisation that this state of cognitive paralysis was entirely medication induced, the onset fitted appropriately with my prescription history and this subsequently pushed me to wean myself off this drug. I started to wean myself off over 4 weeks. This length of time was the 'slow taper' that many GP's advocate for. I started cutting my pill in half one week at a time until there was nothing left a month later. About 1 to 2 weeks after discontinuation, I was sitting watching TV when all of a sudden I got a horrendous sharp jolt into my head. Almost like a bolt of lightning, or as if a sharp pin needle flew through my head. I called it a sharp shooting pain, even though it wasn't exactly painful. However it was startling, so much so, it made me duck for cover on the floor of my living room. I called the doctor-on-call, they

dismissed my concerns and told me it was anxiety. "Take some water and lay down" they said. Little did I know, this was the beginning of an antidepressant withdrawal syndrome which would ruin my life for the next 2.5 years.

I was normal the next day. Then as the days followed, these brain jolts or 'brain zaps' as they're called became frequent and happened about 50 times a day - although subtle. I also was experiencing visual disturbances - a small bright dot would zoom across my vision several times a day, almost like a shooting star with a trail behind it. I knew something was wrong. I contacted my optician to get my eyes checked. They confirmed all was perfect. I then tried to put it to the back of my mind. The symptoms came and went. I then started getting sharp shooting pains in my chest, along with isolated episodes where I felt like I was free-falling or floating momentarily. I visited my GP once again. They told me my heart rate was through the roof. I was ordered an ECG. All seemed fine, however my heart was still racing, for whatever reason. They placed this down to stress. Fatigue crept up on me, and I often felt like I wasn't able to carry on my day. Strange reactions to substances - coffee and alcohol began out of the blue. I didn't get the same buzz of coffee, it did nothing. Alcohol began to give me palpitations - I was very tolerant of alcohol all my life and this came as a shock. As an avid gym goer, I attended the gym 4 - 5 days a week. I loved the freshness after a gym session, the endorphins afterwards and the improvements in body composition. I was certainly dedicated to my fitness and often pushed myself to new levels in attempts to give my body a proper workout. However, my capacity to deal with exercise began to diminish. I began to feel very odd sensations in my head when weight lifting. The best way I could describe it is as if my head had tingled momentarily, or clicked inside - which immediately drained me of energy to continue. I just immediately felt odd. I felt the urge to go sit down and didn't exactly feel 'well' when people questioned if I was okay. This sensation happened here and there, and sometimes in the kitchen whilst preparing food. I just didn't feel right. This sensation would overcome my whole body. The head sensation would flow from the top throughout my body which led to a queasy stomach, a mild fatigue, momentary dizziness and slight panic. I had to sit down. It passed after a few minutes.

For an entire month I suffered from this extremely irritable sensation in my legs at night - 'Restless Legs Syndrome'. It would haunt me for the next month. It felt like an internal jolt of irritability went down my legs and it made it absolutely impossible to sit still. I had to move them to ease the intense sensation. I had to stand and watch TV while I stomped my feet on the ground to bring some relief. It often kept me awake at night. I thought this was separate to all my other symptoms that I was experiencing progressively over months and much to my ignorance - this was part of a much bigger issue at large. All these random symptoms and isolated incidents were withdrawal symptoms building over the months following my discontinuation of Citalopram.

A total of 5 months after my discontinuation of Citalopram is when all hell broke loose. I woke to a sensation that I was free-falling. I took a very frightening reaction out of the blue - it almost felt like a seizure. It felt like I was shrinking, my eyes lids started fluttering uncontrollably, I had a great sense of impending doom and my heart was pounding out of my chest. I called the ambulance and they took me to A&E. I got checked out and my bloods were perfect. They had no idea why I had such a reaction. They sent me home. Then my symptoms slowly got worse. I couldn't sleep, I had 'hypnic jerks' every time I tried to fall asleep - it made you feel

like you were falling off a cliff every time you drifted off to sleep. My stomach was in bits and I couldn't eat for several days. A terrible sensation began whereby I felt like I was rocking, swaying and bobbing as if I was on a boat. This is my most disturbing symptom and has plagued and haunted me for the past 2.5 years. After several trips to my GP, I have been diagnosed with an array of conditions – Labyrinthitis, Vestibular Neuronitis, Panic Disorder, Lyme Disease, Migraine etc. I have been provided with numerous medications to treat these over the period of two months to no avail. My main complaint was that my brain zaps (sharp jolts to my head) were getting more severe. These brain zaps were of a different nature and force to those felt in first month of withdrawal - they were short lived, subtle and resolved and I never experienced them again till now. I was experiencing at least 100 a day at this point for at least a month. My GP thought nothing of it, they just advised an upping of dosage or to switch to a different medication. This practice is almost like throwing anything at the wall to see if one sticks. I find this a truly disturbing and an extremely careless approach to medical care.

I tried to reinstate the medication, after one of many dismissive and unhelpful GP's hinted that this may be connection to my discontinuation of Citalopram, but favoured it to be viewed as a 'return of my original illness'. To make it clear, I have never suffered physical illness in my life, prior to Citalopram. I have never needed antibiotics and I have never even had the flu, only minor colds. This notion of a 'return of my original illness' didn't sit well with me. This reinstatement of Citalopram at 8 months out made me 10 times worse and nearly rendered me physically disabled - I had seemingly developed hypersensitivity to the medication, something which conflicted with my previous ease of use. The reinstatement forced me to be admitted to hospital. They had to monitor me as I had lost the ability to walk. I felt like I was continually free-falling, as if there was no ground beneath me. My head rotated physically in a circular fashion with a heavy force in my head, and my eyes closed involuntarily for every rotation of my head. I was severely confused and felt unable to stay conscious. My body temperature was extremely high, yet I shivered with how bitterly cold I felt – I had rigors. My bowels routinely emptied every 2 hours with preemptive warnings of loud noises originating from my lower abdomen each time. I had to crawl to the bathroom, as I was unable to use my legs. I literally thought this was how I was going to die. It certainly felt like I was dying. All bodily functions were seemingly shutting down. The A&E doctor informed me they were going to test for Leukemia and Lymphoma. My results came back clear. They monitored my heart rate over the day and provided chest X-Rays, with no clear sign of reason behind my symptoms. I was later released as my vitals returned to normal. When these symptoms improved slightly over several days later I felt like I was walking on trampolines, where the whole ground would bounce or quake every time I step foot on the ground. It took 3 months for me to recover back to baseline after that one tablet. I avoided that GP due to their negligence towards my life. I attended another GP in my practice and voiced my concerns of my reaction and how I still felt unbearably sick – so much so that I was still clinging onto dear life. She reassured me trying a different antidepressant wouldn't result in the same reaction. She believed that I had somehow developed a reaction only to Citalopram – I felt this to be very odd considering my continual ease of use of Citalopram for 2 years. She prescribed Sertraline 200mg. My heart sank when I heard the high dosage. I begged to have it reduced to a much smaller dose. I recommended 50mg. This was refused and I was told "this is the manufactures minimal therapeutic dose in order for it to

have any affect". I was heavily reluctant to take it, I initially refused but she insisted that I would never 'get better' if I didn't resume antidepressant medication treatment. At this point I grew paranoid as to what my GP's were leaving in the notes to each other - perhaps "severely mentally ill patient in need of psychiatric drug treatment to ease psychosomatic symptoms". All I wanted was the symptoms to go away, so I felt trapped on what route I should take. I refrained from taking Sertraline for a week and I strongly resisted each time I attempted to take it. I would gag every time I tried to put it near my mouth. My body knew not to consume it, but I felt pressured into doing so. "Trust your doctor, they know best", that's all I could say to myself to build up my courage. Unfortunately later that day after I took the tablet, a similar reaction occurred, but to a lesser degree – nonetheless just as serious. I was admitted to hospital once again. This time they realised a trend in symptoms and after assessment of hyper reflexes and other criteria I was diagnosed with Serotonin Syndrome and was told to never take another SSRI again, regardless of what my GP says as it would be a danger to my life. After those two terrifying experiences, I can firmly say I'm scarred for life by the medical profession.

Upon return to the GP who prescribed me Sertraline, I challenged her belief on why I was taking such a severe reaction and why I was suffering with these symptoms. She mentioned that antidepressant withdrawal lasts no more than 6 weeks and it "would be well out of your system by now. It's impossible". Do I trust any GP's advice now? No. The saying goes – "Fool me once, shame on you. Fool me twice, shame on me". I felt endangered and a fear of the medical profession ensued. I've also developed a phobia of any prescriptive medication due to the harm it has caused me. I've lost my trust in doctors and this is a very serious position to be in, as I may depend on their advice at some point in the future. This is a direct result of medical ignorance of antidepressant withdrawal and subsequent dangers surrounding being in withdrawal that require carefully considered recommendations, such as avoiding reinstatement at such a late stage in withdrawal due to a severe risk of adverse reaction and intensifying withdrawal. Doctors desperately need education in this realm of medicine. It can cost lives. It could have all been avoided.

I'm now crippled with a list of symptoms which I've suffered with for 2.5 years including but not limited to; Tinnitus, severe eye floaters, a rocking/swaying sensation like I'm on a boat, pulsating vision, 'glitchy' vision (outlines of objects distort), a feeling that I'm being pushed and pulled by the blood pumping through my veins. I have a burning/prickling sensation in my hands after I eat certain foods. Chronic muscle twitches. Paresthesia occurs in simple body positions and often can lead to total numbness of a limb or body part. I suffer from memory loss, cognitive decline, inability to concentrate and I regularly lose my train of thought when speaking. I often forget what I've just been told a few minutes ago. I must reiterate, I'm only 25. I have adverse reactions to caffeine, alcohol, most OTC medications (even paracetamol and supplements), foods, stress and exercise. All of them heighten my symptoms. Prior to discontinuation I use to drink 2 coffees a day, and was an avid gym-goer - often running on a treadmill 4-5 days a week. Now I can't even jog slightly without increasing my symptoms. Any attempt to lift weights or run results in severe imbalance and visual disturbance - it feels like I've an invisible force field right up close to my eyes, causing an odd combination of physical force and visual disturbance. It almost feels like I'm drunk post-exertion. I'm a shell of my former self. I'm in antidepressant withdrawal and not one GP will acknowledge or take ownership for it.

I've struggled to leave the house. I have been so crippled with debilitating symptoms for such a long time. I consider myself privileged to have secured employment, after a year into my withdrawal I was just about able to function and cope. The financial burden of not being able to work (and denied benefit) has nearly cost me my opportunity to get a foot onto the property ladder which I had long made plans for but unexpected health issues almost made that plan a very near distant thought. I take each day by day in the workplace. It certainly is a challenge as not one person can see that I'm struggling with a chronic illness. I look fine at face value, but inside I'm dealing with unimaginable symptoms. I guarantee it would test the most stable of people. It truly is a miracle that I haven't been fired yet.

They should provide training to GP's on the dangers of antidepressants, as they seem to disregard any side effect as 'being all in the head' - as if people prescribed antidepressants are immune somehow to medication side effects, even if they are well known or cited on the medication leaflet. I believe patients can only give informed consent to taking antidepressants if they've signed a consent form which clearly lists that antidepressant withdrawal can occur and can be protracted - taking many months to years to recover. Here is the medical evidence to prove it can last far beyond a few weeks, months and indeed years –

<https://www.karger.com/Article/Fulltext/371865>.

Please note these very important statements in the above study:

- “When treatment with a CNS drug is discontinued, patients can experience classic new withdrawal symptoms, rebound and/or persistent postwithdrawal disorders, or relapse/recurrence of the original illness [6, 9, 14] . New and rebound symptoms can occur for up to 6 weeks after drug withdrawal, depending on the drug elimination half-life [2, 3] , while persistent postwithdrawal or tardive disorders associated with long-lasting receptor changes **may persist for more than 6 weeks after drug discontinuation.**”
- “Withdrawal symptoms can be relatively short-lasting, lasting for a few hours to a few weeks with complete recovery, **while others may persist and last for several months** [1, 15, 16]”
- “Fava et al. [1] have proposed using the terminology ‘withdrawal syndrome’ to replace the term ‘discontinuation syndrome’, which has been most often used to describe SSRI withdrawal. They have recommended the use of withdrawal terminology for SSRIs, rather than discontinuation, because the term discontinuation syndrome minimizes the consequences of SSRI withdrawal, separating it from other CNS drug withdrawals”
- “Recently, Fava et al. [1] have conducted the first systematic review of SSRI withdrawal. The authors analyzed 23 studies (15 randomized controlled studies, 4 open trials, 4 retrospective investigations) and 38 case reports of SSRI withdrawal, and **found both early and late onset, and short and long duration of withdrawal symptoms. This important report provides substantial evidence for SSRI withdrawal prompting the need for a new classification of withdrawal phenomena associated with SSRIs.**”

- New withdrawal symptoms reported with SSRIs include a wide range of symptoms, **both physical and psychological** [1] , and are found throughout different systems in the body ( table 2 ). New withdrawal symptoms described in the literature include flu-like symptoms, headaches, nausea, diarrhea, dizziness, decreased concentration, sleep disturbances, dysphoria, irritability, and restlessness [1, 12, 22]
- In table 2 , we present withdrawal symptoms from the recent systematic review by Fava et al. [1] and **indicate new symptoms during SSRI withdrawal that seem to be specifically related to serotonergic pharmacology** [27, 28] . These specific serotonin-related symptoms include diarrhea, flu-like symptoms, dizziness, myoclonus, electric shock sensations, and premature ejaculation.
- Persistent postwithdrawal disorders have been described with different classes of CNS drugs (e.g. protracted insomnia for alcohol and benzodiazepine withdrawal [10, 36] and major depression/dysphoria for cocaine and amphetamine withdrawal [10, 23] ), and even more so with specific drugs (e.g. quetiapine and paroxetine) within a drug class [6, 15, 16, 33] . **We now have increasing evidence for postwithdrawal disorders with SSRI long-term use** [6, 15, 16, 26, 37] .
- They **persist at least 6 weeks** after drug withdrawal and are sufficiently severe and disabling to have patients return to their previous drug treatment. When the previous drug treatment is not restarted, **postwithdrawal disorders may last for several months to years**. They may resemble rebound symptoms being more severe than the original symptoms, but these disorders persist at least 6 weeks in contrast to rebound symptoms and Table 4.
- Fava et al. [16] conducted a study of gradual SSRI discontinuation in panic disorder and found that 9 of 20 patients (**45%**) **experienced new withdrawal symptoms, and that 3 of the 9 (33%) patients treated with paroxetine had postwithdrawal disorders at 1 year of follow-up**
- Second, **we recommend gradual tapering over a long period of time to discontinue an SSRI, for example, over several months if clinically appropriate**. According to most studies [1, 15, 16, 20, 29] , even with gradual tapering, withdrawal symptoms still occur. However, **gradual tapering, rather than abrupt discontinuation, can help to control the severity of withdrawal symptoms**
- **After 2 years of maintenance treatment, many types of persistent postwithdrawal disorders may be observed**. We recommend re-evaluation of overall treatment and management after 2 years of continuous SSRI use, considering the possible use of other therapies, whether as adjunct or alternative treatment.

- **It is most important to recognize persistent postwithdrawal disorders to prevent unnecessarily high doses and prolonged treatment.**

A massive question remains over the medical profession as to why they are not following the guidelines and evidence of studies conducted on this? Rather than making their own judgment on certain matters, evidence based medicine is of utmost importance. Refusal to acknowledge antidepressant withdrawal lasting more than 6 weeks (often can last 18 months – 5 years) is entirely distressing to a patient who is struggling to remain hopeful of their withdrawal syndrome improving. Complete and repeated denial of antidepressant withdrawal's existence and indeed it's protracted nature by GP's and other doctors fuels anxiety and suffering. This needs to end.

The government should provide a compensation scheme to those patients neglected by their doctors and the medical profession for putting them through unnecessary hell and refusing to acknowledge their withdrawal symptoms and continuous suffering. Many patients have such severe withdrawal that they end up taking their own life, as not only will no medical professional acknowledge their symptoms, but they won't assist them in anyway, other than putting them back on the offending medicine which is essentially toxic to them in withdrawal. Doctor's wouldn't sit idle whilst someone was suffering heart attack symptoms, why are patients in withdrawal treated any different?

There is an urgent requirement for effective communication and training on the dangers of antidepressants, as they seem to disregard any side effect as 'being all in the head' as if people prescribed antidepressants are somehow immune to medication side effects, even if they are well known and cited on the medication leaflet– this communication should be spread throughout the medical profession and it must be ensured that it filters down to training in GP practices. I believe patients can only give informed consent to taking antidepressants if they've signed a consent form which clearly lists that antidepressant withdrawal can occur and can potentially be protracted - taking many months to years to recover.

There are many patients being left in limbo by being misdiagnosed (and subsequently further medicated) with other conditions, when in reality its actually prescription drug withdrawal causing the mysterious symptoms. The term MUS (Medically Unexplained Symptoms) requires review in respect of this. The government has a responsibility to legislate to stop this malpractice. People's lives are being ruined with disabling protracted withdrawal syndromes which they seek validation for, and require necessary support networks to manage and limit their suffering.

To conclude, for 2 and a half years I've been misdiagnosed with other conditions. I've never even been sick in my life up until coming off an SSRI (I've never even had a flu or needed antibiotics). I feel a sense of acknowledgement today by submitting this. Various news outlets are sharing this headline and drawing attention to antidepressant withdrawal on the back of the Scottish Parliaments movement on this issue - although antidepressant withdrawal/discontinuation syndrome is masked under some of the sensationalist phrases of text related to benzodiazepines and other drugs gaining much of the attention, it's certainly there nonetheless. It's an acknowledgement in the public arena that has long been disregarded by many of my GP's. It's seriously messed with my head and such deep denial has made me

question myself constantly every day - is this REALLY withdrawal? I now know it is and much of my suffering over years could have been eased if that knowledge had of been shared with me and necessary physical and mental support was provided. I relied heavily on online evidence which stands up to nothing when trying to convince family and friends. This issue needs rectified with urgency.