

PE1651/MMMMMMMMMM

Dr Edward White submission of 24 December 2018

Compared to many people who have already submitted their experiences to this petition, I think I got off quite lightly during my brush with prescribed medication withdrawal. That's not to say it was any the less devastating, shocking or unacceptable that I should have been misdiagnosed by doctors and psychiatrists, prescribed more drugs which probably made things much worse and generally made to feel that it was my fault, for merely wanting to stop taking a psychiatric medication safely.

That last point has left me with emotional scars, which are healing, mostly through the process of supporting campaigns to grow awareness of the horrific effects of the overuse of prescription drugs that many people experience. The other point that caused me great angst was quite simply not being believed. Psychiatry and medicine appear to be in complete denial that the drugs they prescribe can cause such total devastation when people want to stop taking them.

I was first prescribed an antidepressant in 2009 when I was struggling through the horrendousness of the death of my partner's mother in a car crash, combined with a great deal of pressure at work. The latter was acknowledged by my employer and things changed, I gained experience and the stress went away. I had six weeks off work. The former was difficult for the whole family and is not something I want to happen to anybody ever again. But it will and in my opinion, it does not require drug treatment. People need to talk and be taught coping strategies.

Anyway, I went to the doctor and was told I had done the difficult bit i.e. admitting I needed help in the form of medication, with the stress and grief I was experiencing. I was prescribed Citalopram first and I remember it making me feel very anxious. I experienced a sort of out of body experience, which I now know is often reported as derealisation and depersonalisation. I also felt high, and acted out of character.

There were no warnings of these possible side effects. I went back to the doctor and was prescribed Valium to help 'get me on to the drug'. I couldn't tolerate the citalopram side effects and stopped the drug. The last thing I remember was the next day, after taking citalopram for only two weeks, was feeling very sad and bursting into tears for no reason. I also acquired a low-level tinnitus from citalopram which never went away. Withdrawal? It didn't last thankfully.

I went back to the doctor and was prescribed venlafaxine at an initial dose of 75mg. I had few side effects to start with. The drug seemed to work. Undesirable side effects did develop along the way – frequent urination, drowsiness during the day, night sweats. I took it for about 10 months and decided I wanted to stop. By this time, I was taking 150mg per day. Dropping to 75mg was fine but then I started to feel quite angry and short tempered for no reason when I tried to lower the dose further. A locum doctor prescribed a liquid formulation of the drug and I was able to taper off slowly using instructions someone had posted on the internet. It took 9 months.

I was well for a couple of years but then started suffering low mood and suicidal thoughts. I had never experienced intrusive thoughts like this before. There was no 'life-event' as a causative factor as the doctors call them and I was persuaded that the depression was caused by innate issues. At this point in time I knew no better and accepted the diagnosis. I now know that the evidence for biological depression is poor.

I was started on sertraline. I can't remember the dose. I think it helped for a while, but then stopped 'working'. I can't remember the details. I just remember persevering for about 2 months. When I could no longer stand the mood changes and general unwellness it seemed to be causing, I returned to the doctor and asked to go back onto venlafaxine.

The doctor said X mg of sertraline is the equivalent of 75mg of venlafaxine and I was cold switched from one drug to the other. There was no cross tapering. This was pretty horrendous although my memory of it is quite poor. I did go back to the doctor to explain it was making me feel much worse, and I do remember being asked if I was thinking of harming myself. I was not. I just wanted to feel better. After a period of time I cannot recall, I did and was told the 75mg of venlafaxine would be a lifetime maintenance dose. Again, I didn't really question this, thinking that it would be safe to take for an extended period and that I had managed to stop it safely and successfully once, so I could probably do it again.

Over the years, the side effects started to become more apparent. These included drowsiness and sedation during the day, increased frequency of urination, especially at night, increased appetite (I always wanted to eat, particularly sugary foods, so I gained weight) and emotional flatness or bluntness.

The other thing I started to notice was the effects of missing a dose. Early on in 'treatment', it would take between 12 and 24 hours to manifest itself if I missed a dose – I would get a 'swimmy/whooshy feeling in my head. My vision was affected, in that my eyes didn't appear to keep up with the movement of my head; there was a strange lag. I would start to get loose bowels and nausea. Taking the next dose cleared all this up, and on I went. By the time I decided I wanted to stop, the effects of missing a dose would become apparent about 2 hours after missing it. This suggests to me I was becoming tolerant to the drug?

In 2017 I had been taking the medication for about 6 years and decided I wanted to stop. I went to see my GP and he didn't try to persuade me not to. He prescribed a pill form of the medication that could be easily broken up and liquid to cover the lower doses of the taper, saying "I should be alright" with my planned 5% dose reductions on each step. I haven't forgotten those words.

Buoyed by my previous success at tapering I thought I could go faster this time and took about four months to taper. During this period, I did experience some mild withdrawal symptoms, mainly visual disturbances and dizziness, with some gastro intestinal upset. The taper started in mid-June 2017 and ended in late November on a dose of 4mg per day.

Nothing could prepare me for what followed.

The symptoms I suffered over the next few weeks and months were manifold.

Physical - nausea, diarrhoea, dizziness and dizzy feeling in the head; visual disturbances (my optician told me this is because the drugs impact on the optic nerves as well); mild but constant headache; mild tingling sensation in the face; intolerance of and acute sensitivity to loud noise, music, sweaty hands and feet; tinnitus; loss of appetite and associated weight loss (about 1,5 stones).

Emotional – depression like I've never experienced before, like a pit of despair, uncontrollable and unending; severe anhedonia, which I had never experienced before; anxiety like I've never experienced before for no apparent reason - nonspecific anxiety; situational anxiety (mainly thinking I would never get well and lose everything); panic attacks which I've never experienced before; very poor tolerance of stress; hyper emotional and very sensitive to emotional thoughts; acute insomnia; irritability; poor concentration; mood swings over a very short time period for no apparent reason, again like nothing I've experienced before. In fact, I can safely say all these symptoms were new in terms of intensity and occurrence.

As an example, I was sat on an aeroplane coming back from a business trip for work, listening to music and feeling fine. Then suddenly, like a switch had been flicked in my head, my mood dipped severely. No thought process was attached and there seemed to be no reason for it.

I did not suffer any of the more emotional, thought based symptoms like low self-esteem (other than, what the hell is happening to me and my life??). I didn't have any negative thoughts towards myself as such. There was no self-loathing or self-blame for what was happening to me. I just felt like these symptoms were making my life too unbearably miserable. That I just wanted it to end. The main emotion was guilt at wanting such a negative thing to happen and the impact it would have on those I love, particularly my wife and children. I kept trying to work out ways I could leave them with the means to carry on living their lives in some comfort. This was obviously impossible to achieve.

The emotional symptoms came and went. I had one or two good days followed by 2-4 days of feeling depressed, anxious, etc. It started to become very frightening.

I spoke to several doctors at the local GPs surgery by phone, asking for advice about what to do and received very different advice from each – go back on venlafaxine; don't go back on the venlafaxine; try a different class of AD meds; tough it out, it will go away; if you don't produce enough serotonin you need medication, it's like being a diabetic who needs insulin, etc. In the mean time the symptoms intensified. I turned to the Internet.

On the advice of the survivingantidepressants.org forum, I reinstated the 4 mg per day of the venlafaxine I ended my taper on. This was in late November, five weeks after I'd stopped the drug. Just after reinstating this low dose of venlafaxine, which did kill off the withdrawal symptoms, almost completely in 24 hours (not withdrawal, then??), I also started mirtazapine as offered by a doctor (I was desperate by then).

I could not tolerate the mirtazapine, even at a low dose of 7.5mg. It made me feel much worse, caused very disturbing mood swings – I could feel myself dipping into horrible depression and then literally, a few minutes later mood would pick up again and I would start to feel elated. The only good thing it did was sedate me sufficiently to enable a full nights sleep. I had to stop taking it after about two weeks.

Unfortunately taking and stopping it also messed up the benefits of the venlafaxine reinstatement. I still regret it to this day as evidence suggests that if I'd stabilised on the low dose of venlafaxine I may have avoided the horrors that followed.

I went back to the same doctor who prescribed the mirtazapine not long after stopping it and asked if I could go back onto venlafaxine because the withdrawal symptoms were becoming intolerable. By this time, I was signed off work completely as I was too ill to cope.

He said yes but that I should be very careful about how I did it and to do it in small increments (without advice on how big these increments should be). I went away and increased the dose from 4mg per day to 11mg per day. This sent me into a complete tailspin. Within 24 hours I became completely hyped up and agitated, totally unable to eat or sleep and having very strong and repetitive suicidal thoughts. My tinnitus amplified considerably. I remember pacing around the house not knowing what to do with myself. It was extremely frightening and a day I will never forget.

I assume this was a reaction to the reintroduction of too much of the drug, too quickly and due to the state of withdrawal I was in. Whatever the cause it was clear that I had become very sensitive to a drug that previously hadn't caused me too many dose related issues.

As I was in such a bad way, my wife phoned the doctor and I was referred on to a primary care liaison mental health team in the NHS. At this point I was still taking the 11mg of venlafaxine each day in two divided doses to stave off further withdrawal symptoms. Then I was prescribed 30mg of duloxetine per day. A psychiatrist I never met told my doctor that this would enable me to taper off the venlafaxine.....some hope! I tried to reduce the venlafaxine (by 5%) and the reaction was terrible.

My primary point of contact in the mental health team was a prescribing nurse. I only had phone contact at this point (mid-December) and it was clear the service was severely over stretched. From the description of my symptoms she accepted I was in withdrawal and prescribed diazepam to get me through the Christmas holidays with some comfort. This worked quite well for the anxiety but I was taking about 8mg of diazepam a day for about a month, the maximum time it is safe to do so. I had to taper off over 2 months or so. As I did so the anxiety that was being suppressed by the diazepam got gradually worse and worse.

So, into the new year 2018. At this point I was a wreck. Deeply depressed and very anxious and spending long periods of time at home in bed, not wanting to get up or go out at all. As I tapered off the diazepam the anxiety just got worse and worse. I have never felt so depressed and debilitated in my life before and I never want to go there again. I was very suicidal and it's only the support of a few very good friends and having my wife and children around me that kept me alive.

One thing that was very noticeable was the diurnal nature of the symptoms I was experiencing. I would wake in the morning with a very strong spike of anxiety and racing heartbeat, which I now know was probably caused by cortisol, as per the many descriptions other people have written on online forums and personal testimonies. I would also feel very depressed. By the evening (6-7pm) the symptoms would have calmed considerably and some days I would go to bed feeling like there was nothing wrong at all, only to wake the next morning and start the cycle all over again. It was a hideously torturous existence. This went on for 3-4 months, during which the duloxetine was increased to 60mg per day and then 90mg. I could not tolerate the latter. It caused severe agitation and it was reduced back to 60mg. It never worked. I had minor withdrawal from stopping much later on, but thankfully only physical symptoms.

I was also prescribed quetiapine (25mg, about mid-February I think) by the prescribing nurse in the hope it would augment the duloxetine and make it work. It didn't and I still have to taper off this drug.

As I was in such a terrible state of anxiety and depression and still having constant suicidal thoughts I was referred on to what is called an Intensive Team – read 'crisis' team here – which meant I was receiving home visits from field nurses every other day. I was also introduced to another psychiatrist. I met with her and described what had happened to me when trying to stop the venlafaxine and how I thought I had gone into withdrawal, etc. Her diagnosis was a relapse. She paid no heed to the withdrawal explanation. No real surprise I guess.

At this point I should say that the previous depressive episodes I have experienced in my life are not even on the same scale as the way I was feeling at this point. I had never before had the deep depression or debilitating anxiety I was suffering at this point. I had no interest in anything. Motivation was at rock bottom. I felt like my life was in tatters. I wanted to die. I live near a railway line and had many hideous thoughts about ending my life that way.

The psychiatrist increased the dose of the quetiapine to try to kill off some of the anxiety. It went up to 50mg, taken at night, so at least I was able to sleep as it is so sedating. I'm not sure if it helped the anxiety, but at this point I didn't care, literally. I was convinced my life was over and that I would never recover.

I was also advised to restart the venlafaxine (increase from the 11mg I was still taking) by 3 mg every 5 days, using the liquid preparation I had access to. This advice came via the psychiatrist, from a pharmacist I never met. I was very frightened of doing this due to the hideous reaction I had previously experienced when I tried to increase the dose. However, I complied as I was in no fit state to fight it. Each dose increase was unpleasant and caused side effects and increased suicidal thoughts, but I progressed, although it seemed so slow and a 'therapeutic' dose seemed so far away. I was patronised by many well-meaning psychiatric nurses who towed the party line – "you are so sensitive to these drugs" (even though I'd been able to start on a 75mg dose with few issues in the past). So why now was I reacting so badly to a few milligrams of the same drug? Despite repeatedly asking the question, "Why?", no one, including the psychiatrist could or would answer it.

In the mean time I was discharged from the crisis team to a community mental health team sometime in late March.

This meant a new psychiatrist (who was also not interested in the withdrawal explanation). When I met with her I was taking about 30mg of venlafaxine per day and still reducing the duloxetine. She suggested I should increase the venlafaxine dose more quickly, by 10 mg per week. So even though I was very anxious about it and continued to experience intensified suicidality at every dose increase, I did it and I got to 37mg and was able to take a slow release version. I also switched from a liquid preparation to tablets which could be broken up and didn't caused the spike of drug absorption (and hence the intensified side effects) that the liquid did, presumably because it is taken up so quickly by the body. I was able to increase the dose more quickly than planned. By the time I was at about 65mg, things had improved considerably. The depression lifted and the anxiety went away. No more suicidal thoughts. This happened in less than two weeks and I've ended up back on 75mg XL per day. The relief was immense. Motivation returned. I was able to go back to work.

The psychiatrist seemed very surprised by this miraculous recovery when I met with her again two weeks later in late April. I don't know if the dose I have returned to has merely killed off the withdrawal or if it has just worked as AD medication can and made me feel better? It seemed to happen quite quickly. I was told "it does happen but it's very rare"! I think I know which side of the fence I'm on.

The main remaining symptoms I was left with were gastrointestinal upset, tiredness, intensified tinnitus and that morning cortisol spike was still there, albeit not as strong as before. Running and vitamin C really helped with the latter. I started taking about 2000mg of vitamin C before bed and I am also tried phosphatidylserine for a month. The morning spike abated over the next couple of weeks. I am assuming the tiredness was a result of being hyped up on cortisol and adrenaline for the previous 3-4 months. The gastro effects have disappeared but the tinnitus is still there and shows no sign of abating. It is listed on the venlafaxine PI leaflet as a side effect and a discontinuation symptom.

So, I was left on 50mg of quetiapine and asked the psychiatrist how much longer I need to take it. She suggested, in writing, I could taper off at 12.5 mg per week. I decided to take a little longer and tapered down over two months. When I stopped in July this year at about 2mg I immediately started to feel very agitated, my mood lowered considerably and I got diarrhoea, nausea, insomnia etc. I was scared. I thought my nightmare was retuning. The psychiatrist said not and that I should increase the does of venlafaxine to 112 mg per day. It did not help. I stuck this out for about two weeks and the symptoms intensified. I decided to reinstate the drug to 12.5mg, after being told by phone, via a nurse, by another psychiatrist I had never met, to go straight back to 50 mg. 90% of the symptoms abated within 24 hours. Going up to 25 mg killed off the rest in the next couple of days; I could then go on holiday with my family without any issues.

I am now tapering off the quetiapine very slowly. I expect it to take 12-18 months to get off it safely.

My trust in doctors and psychiatrists has been shattered by this experience. I'm really not sure what I am being treated for anymore apart from staving off withdrawal from medications I have struggled to stop safely.

One final point. I had an appointment with my GP after this episode to sort out prescriptions etc. His closing shot in that appointment was "Let that be a lesson to you. Don't mess about with your medication again". I managed to hold fire with a verbal outburst. I don't know how.

Apologies for the long read. I hope this submission is useful.