PE1651/XXX
Anonymous submission of 7 January 2018

The experience below relates to the impact of discontinuation of Venlafaxine, and SNRI antidepressant. I regressed from an amateur international athlete to a very ill, depressed and withdrawn individual.

Background
I had presented at my GP in early 2016 in an anxious state due to concern about symptoms consistent with a blood clot (anxiety the result of a misdiagnosis of a blood clot in the brain in 2011). It is important to note here that had the ultrasound been carried out this first medication would not be required, neither would the repeated GP consultations that followed.

I waited 8 weeks for the ultrasound appointment which proved negative. Prior to the appointment I remained in an anxious state for those 8 weeks, resulting in a prescription for propranolol. I suffered numerous side effects and was prescribed atenolol.

Prescription of SNRI antidepressant
I experienced further side effects from atenolol and was prescribed an antidepressant, venlafaxine.

During this time I also sought private support, undertook a significant amount of effort on my part to deal with the anxiety. I had referred to an NHS support service but an appointment was not offered until many months later. The ultrasound proved negative and having dealt with my anxiety in the appropriate, non-medicated manner I chose to stop taking the venlafaxine following the published and publicly available guidance from NHS Education for Scotland (NES). The guidance was previously available but has since been removed after my complaint in April 2017. It is noteworthy that the guidance had not been reviewed since 2005 yet was still publicly available. You can also access the 2012 archive of it here: https://web.archive.org/web/20120505020556/http://www.nes.scot.nhs.uk/media/344033/stoppingantidepressants.pdf

The NES guidance recommended tapering off the medication over a period of two weeks (as I had been taking it for **only two weeks**). After I followed the guidance I began to suffer a range of unexplained and traumatic symptoms that limited my ability to function on a daily basis.

The following were experienced after discontinuation:

- Pressure headache all of the time
- Severely disturbed sleep, often alert throughout the night
- Feeling of a fever, burning up yet temperature was normal
- High blood pressure
- High heart rate (tachycardia)

- Upon waking there was a disturbing surging sensation throughout the body combined with an unexplained pulsing/throbbing throughout the body to the head that is not related to the heartbeat
- Headache upon waking that I would describe as a hangover and concussion rolled into one
- Chronically slow digestive process causing pain, headaches and general malaise
- An extremely disturbing sense of non-reality, dulled senses and inability to determine whether life at that time was real or a dream
- Severe depression

None of these were experienced whilst taking any of the aforementioned medication.

The above symptoms were refuted by my GP other than the blood pressure which was simply recorded. During the consultation she stopped writing them down as I progressed through the list. **I ask the Parliament to consider how this situation would impact on a patient presenting with the above symptoms. Does the Parliament consider this appropriate? Is this the person centred NHS you want to see?**

I also ask the Parliament to consider that these medications are being prescribed based on symptoms that cannot be measured yet the same doctors refute symptoms that cannot be measured after taking the medication. Is this acceptable?

My GP agreed to refer me for further investigation, only of the digestive problems. Upon meeting a consultant at the hospital I was tested for numerous conditions, including terminal illnesses. This process had a significant impact on me as someone with a predisposition to anxiety due to mistakes made at the same hospital.

The tests returned negative. I was offered more medication (another antidepressant) for the headaches with the speculation that they may or may not help. I chose not to take this up given the speculative approach and problems medication had already left me with.

Reinstatement of medication

Abandoned by the health service and unable to find an explanation or support for my symptoms I was fortunate enough to find a significant amount of patient testimony of the types of symptoms I was experiencing. Others who had experienced these problems advocated for a very gradual tapering method for discontinuation of the medication.

They also proposed that reinstating on the medication might alleviate the symptoms. With no other choice, in July 2016 I tested this with a reduced dosage despite my own scepticism. There was an immediate impact. At the time I wrote "*Felt like myself for the first time in months within an hour. Pressure in head released, feeling of burning up was gone, even the pulsing in the stomach reduced.*"

It took me 10 months to reduce the dosage to zero by 10% of the current dose each time (suggested by patients with lived experience of this). The symptoms outlined above presented numerous time throughout those 10 months often severely. The reduction took this length of time based on the guidance of other patients – outlining that further reduction should only take place when symptoms have ceased. During this period I struggled with the symptoms outlined earlier, the dependency on this drug and the lack of support. After breakfast and dinner I would have to cut up and weigh medication, carrying what I know considered to be 'poison', a pill cutter and micro scales with me if I went anywhere for these meals (which resulted in me rarely leaving the house at these times or overnight). My strength of will suffered significantly during this time and at low points I considered suicide. I do not use that term flippantly. It is extremely uncomfortable to admit to this and I do not recognise this as the person I now am but this is what it did to me.

I will never get those 10 months back. My sporting career is now over due to my age. Were it not for the support of my partner and others who have experienced and still do suffer from this 'discontinuation effect' I might not be here.

I ask the Parliament to consider this patient testimony as evidence and commit to the collection of other patient testimony. I have worked in patient and public involvement in the NHS for a number of years. The guidance I followed from NES showed no evidence of patient involvement despite being published after the NHS Scotland Patient Focus Public Involvement framework of 2006. Much is made of a personcentred NHS. 'What mattered to me' was never considered, much less solicited. There is an opportunity for some good to come out of this appalling experience.