

PE1651/PPPPPPPP

Erin Roche submission of 22 May 2018

My name is Erin Roche and in June 2015 I had my first child. A dream I feared as a chronic migraine sufferer I'd never realise. In August 2016 I met with my neurologist to for a post pregnancy catch up-consultation. I told him I was likely going to re-start, after breastfeeding, a low dose antidepressant I had used prior to pregnancy as I was suffering from low mood and pain.

My Neurologist suggested if I was going to take an something for my mood he would advise me to take Venlafaxine (SNRI) which has been shown to have some effect on headache. This was the start of me losing my life to a pill.

When I started taking Venlafaxine around July 2016 I was suffering low mood and migraine pain. By October my mood was completely haywire. Big highs followed by big drops. I went to my local GP who increased the dose of Venlafaxine. My mood deteriorated rapidly and my mood which was already highly unstable became totally unstable and I was experiencing highs and deep lows within matter hours as opposed to over the week. I thought I was losing my mind. Holding my life together (job and child and home) became almost impossible. I had become housebound and reliant on my Parents and working partner to survive each day.

By Christmas 2016 I was in crisis and suicidal in mood. Desperate. I realised however it was the Venlafaxine that had caused these manic Highs followed by cliff dropping lows. I was now under the local mental health crisis team.

Having asked to see a psychiatrist to discuss medication options I instead received a call from a psychiatrist on a break from a meeting. He told me to stop taking the venlafaxine and prescribed the mood stabiliser is requested. He gave me no taper / reduction plan advice.

I thought I was already in hell so depressed by my own behaviour and emotional state which had gotten so unbearably unstable. I was struggling to get through a day and to be a mum and desperately sad and blaming myself. Once I stopped the venlafaxine (at 37.5mg) hell truly began. I can't even start to explain this period and so will bullet point:

- extreme brain zaps (likened / potentially mini seizures) so frequent and so abrupt I was unable to keep my focus and head still.
- Intolerable (NB - I suffer chronic migraine and delivered a child drug free - can manage pain)
- extreme irritability / rage. I couldn't be around human beings as I was so irritable. (Extremely worrying when you have a child and partner)
- sickness and diarrhoea
- head pain
- uncontrollable crying
- trauma so extreme I didn't feel part Of the world anymore. Sense of not being real.
- head pressure
- Weakness

- inability to cope with the smallest task.

During this time my partner and parents did everything to work out how to help. Every psychiatrist (private and NHS) and pharmacist told us something different with regards to what to do and how to do it (taper or introduce other meds etc).

We were extremely lucky to find, at the point of me being sent off to a detox centre (which would have been completely unsuitable and unlikely for me to have coped with) the Bristol & District District Tranquiliser project who advised that I must reinstate the medication and taper extremely slowly using liquid. They had experience with other people experiencing 'Extreme Discontinuation symptoms' from SSRI's and venlafaxine is know To be one of common ones for patients to experience huge difficulties in its discontinuation by patient.

Though the psychiatrists, pharmacist and gp seemed to be in the dark on what I was experiencing, I have since met with another girl, from my town Who has seen the same GP, we have the same surgery. She, like me was prescribed Venlafaxine by neurologist to treat headache and mood. She has not worked since her own terrifying experience. I am also part of several online groups with between hundreds, to 1000'a whom have experienced Similar or the same discontinuation effects (nightmare) from trying to stop taking the drug Venlafaxine. Most of us are still taking The medication desperate trying To get off it.

Exasperating this issue of severe and lasting discontinuation effects of SSRI, resulting In absolutely loss of livelihoods and relationships etc, is the fact the medications such as Venlafaxine do not come is dosages small enough for users decrease their dose in small enough increments that allow for a much much slower and safer taper. Doctors have their hands tied by what and how they can prescribe and users are having To go to extreme lengths to create smaller Doses (opening of capsules and buying micro scales (0.001) to measure out their own reductions.

My experiences trying to come off venlafaxine, I want to conceive without being on medication) has been the most traumatic and terrifying of my life and it's far from over.

I now give up hope of ever managing with a second child due to the ongoing venlafaxine discontinuation symptoms I am experiencing. This experience feels almost unreal, like a waking nightmare.

I advocate for more research and better education for patients, gps and psychiatrist on 'discontinuation symptoms from antidepressants' and the availability of safe Taper methods for people experiencing difficulties coming off all medications (pain meds / benzodiazepines & antidepressants).

I have been given a liquid form of Venlafaxine however this is not, like the capsule, extended release which I am unable to tolerate. I'm literally stuck right now.

My psychiatrist does not have any answer on how to get off safely.

Please please help effect positive change.