

P1651/IIIIIIII

Emma Jenner submission of 4 June 2018

This is my second submission.

Today is 6.5 years off SSRI antidepressants, or to put it another way, today marks 6.5 years of my life lost to SSRI antidepressants withdrawal syndrome (almost 8 years if include the withdrawal symptoms I experienced 2008-10).

Over these years, I have experienced many weird symptoms that are hard to cope with. The symptoms change daily and even hourly, varying in intensity and form. I continue to experience them.

This is a full list of the symptoms I have experienced/am continuing to experience:

Abdominal cramps, agitation, agoraphobia, appetite changes, huge anger, back pain, dizziness, bloating, body temperature fluctuations, brain fog, burning pains all over my body, concentration loss, crawling sensation on skin, crying spells, dissociation, dizziness, electric shock sensations in head and heart, pressure pains all over my body but mainly face, heightened sense of smell to the extent that certain smells now cause migraines, exercise intolerance, exhaustion, extreme thirst and hunger, weird vision, face pain, pressure pains, organic fear something bad is going to happen such as have a stroke or heart attack, scared of being on my own, scared of taking public transport, flu-like symptoms, stomach problems, headaches like migraines, band around head being tightened, hyperacusis, heart palpitations, heart thumping, heart pain, hormonal imbalances, feeling like am on the verge of a panic attack 24/7, inner shaking, sleep disturbances, waking up at various times in the night and can't get back to sleep, huge emotions, pulsating sensations, blood sugar levels problems, lack of motivation, irritability, muscle pain, light sensitivity, memory impairment, menstrual irregularities, mood swings, nausea, tingling, oesophageal reflux, cramps throughout my body, hyperventilating, repetitive thoughts, skin itchy, skin rashes, sweating, supercharged feeling, tinnitus, mouth pain, symptoms like UTI but appears no bacteria present, heat intolerance, feeling like overheating inside, feeling will faint, the worst panic attacks I've ever experienced, visual distortion, weight issues (initially I lost lots of weight, I gained some back, now I can't gain weight), soft tissue pain, suicidal thoughts, nightmares, not able to focus, try to learn new things but it's like I'm not taking the information in, trouble recalling words (I'm multilingual, trouble occurring across all languages), inability to gain weight, feeling of phlegm stuck throughout my body, feeling like not breathing properly, food intolerances to soy, nuts, gluten, dairy, high histamine, high sugar..highly sensitized system, hay fever like symptoms, react badly to supplements and chemicals.

Day to day I don't know what state I'm going to wake up in. It's awful. It's terrifying. I'm not really living, merely surviving day to day, hour by hour. Currently I'm exhausted, with pressure pains everywhere, joint pain, feelings like a lightsaber is being taken to various parts of my brain, nausea, feeling like something is stuck in my thought, intestinal cramps, upset stomach, very tearful, panicky and insides shaking, insides are overheating, big anxiety, trouble remembering words and grammar across all my languages, trouble sleeping and breast pains. Who knows what I'll be feeling like tomorrow or even tonight. I don't. And I've been living like this

for 6.5 years. I don't go out anymore, rarely leave the house. I don't know how I keep going. I hate my life now.

To my GP this is a "blip," or "recurrence of original problems," but I was a functioning human before withdrawal started. The meds have completely changed my body, all systems have been damaged and disrupted.

Four months ago, my consultant psychiatrist un-patiented me because I refused to accept his diagnosis of MCAS. Every time I tried to talk about SSRI antidepressants withdrawal syndrome he'd shut me down by asking "to what end?" Then he'd change the subject to my diet. My life is ruined by the medical profession, should he not have been trying to actively listen to me about it, to learn as much as he could about it and try and help me heal and stop it happening to other people? Where is his duty of care? He and others routinely prescribe these medicines. He told me himself he doesn't give full information about them because he's scared he'll lose the patients trust?! That's not informed consent?

How can he think that the above symptoms and resulting emotions do not need talking about? Why do I get shut down and un-patiented? When I pointed this out, he asks when I can see him in person? Knowing full well that I'm housebound and live 30miles away. Our normal appointments were Skype or if I was able to face a car journey mum drove me, before he un-patiented me. He really isn't interested in my ongoing experience and seems happy to have un-patiented me. How is it ethical to just abandon someone with so many problems?

Update: now there is a suggestion that maybe he'll come to me and we can chat. However, I'm sceptical any good will come of it. As far as I'm concerned either he decides he wants to educate himself about SSRI antidepressants withdrawal and support me through it, or he doesn't. He can't just concentrate on a few symptoms and ignore the rest. He also can't ignore what caused this. He came and despite my thoughts that it would be a session where we could chat and work things out, it was a "signing off" session. He wanted to know what good things had happened since I'd been seeing him. He didn't want to talk about withdrawal. He dismissed my anger at my treatment. He effectively said I should just take what has happened to me "on the chin."

The name "Selective Serotonin Re-uptake Inhibitor" seems to be wrong, since they are by no means "selective," as there are serotonin receptors all over the body.

They regulate many other neurotransmitters and hormones and body processes. SSRIs affect all Serotonin receptors. Maybe that's why all bodily systems have been so badly disrupted. Patients need to be told this before they start taking them, so they can decide with all information about the meds if they want to take them or not.

Why do the medical profession not care that I have lost so much and become disabled because of their medication?

When will the pharmaceutical companies who make these medications be forced to show all data from their trials?

How many other people have been taken off them too fast, developed withdrawal symptoms, gone back to their doctor and been misdiagnosed with either recurrence of the original problem, or an autoimmune disease, and put back on the offending medication?

How many other people have been put on antidepressants and not told about the risks of taking them? How many others have been put on antidepressants when they really needed someone to listen and validate their experiences and emotions? How many other people have been put on antidepressants and told they "have a chemical imbalance," and so need to be on the meds for life?

How many other people have been put on the meds and then just left on them? How many people have been left on them, reached tolerance, and had to have their dosage increased or changed medication?

How many children are put on these medications whilst they are still growing? How will the medications affect the growth of these children who are put on them?

When will research be carried out to find exactly what the medication does to the body long term? When will research into withdrawal be carried out to find out what percentage of patients experience it? Why some patients seem to not experience withdrawal and why are some particularly protracted? It seems that research has been carried out, and there is already a genetic test that shows whether a person will be ok on meds...

<https://genesight.com/fast-slow-or-in-between-how-your-genes-affect-medication-success/>

Why is no testing done before people are prescribed these medications? From the above article, it's clear that me and others like me are "poor metaboliser" and shouldn't be put on them. Why is this testing not done as standard?

When will SSRI antidepressants withdrawal stop being played down by doctors? Full information about how bad it can be needs to be freely available to patients.

When will NICE change the guidelines to say that once a person has been taken off SSRI antidepressants they cannot be put back on them? When will tapering guidelines be changed to a much slower 10% reduction? Better yet, when will NICE recognise that these medications are dangerous and toxic and shouldn't be prescribed at all?

When will counsellors and psychotherapists be taught more about the meds that their patients/clients could be taking? That way they could also support people coming off medications. Currently I'm reliant on the Samaritans and online groups and forums only.

When will talking therapy be the first treatment for depressed and anxious people? When will emotional literacy be taught in schools as standard? When will doctors take not only symptoms into account, but also lifestyle, diet, family, and environmental factors? On a wider note, it's not surprising increasing numbers of

people are anxious and depressed, austerity measures are hurting everyone apart from the most rich. When will universal basic income be brought in? When will the welfare state be fit for purpose and disabled and unemployed people stop being treated as second class citizens?

How many more lives have to be damaged before the medical profession will take responsibility and admit that SSRI antidepressants are dangerous and dependence forming?

When will doctors be forced to give patients all information on the medication they are suggesting the patient takes?

When will tapering advice and support be available for patients who are in them but want to get off and find doctors standard taper too fast?

I'm incredibly isolated now. I have no supporting doctor for government benefits matters or anything else now, my family don't understand why I'm so ill and don't believe in SSRI antidepressants withdrawal syndrome. And due to my inability to get out I'm losing contact with friends. I'm also reliant on government benefits money since working is impossible in this state.

When will both emotional and financial support be available for those like me who have already had our lives ruined by the meds?