

PE1651/ZZZZZZZZ

Emma Jenner submission of 16 July 2018

I wish to share what has happened to me with SSRI antidepressants withdrawal. I'm in my 6th year of debilitating antidepressants withdrawal and not getting any better. I am ASD too.

I was bullied badly at school, all the way through. When the bullying got worse and I started being threatened with being killed or beaten up, panic attacks started. I buried all of school stuff and only started seeking help when I was at university. In the end I graduated and then saw doctors about it.

When I saw my doctor in 2006 he listened a bit and then I was put on antidepressants told I'd be on them for 6 months whilst waiting for therapy to start. I had problems starting them, had nightly panic attacks and constipation for many months. My doctor said this was normal and to continue, so, stupidly I did. Once I stabilised, I was left on them. No question about coming off.

Therapy did start and was minimally helpful. She helped me learn to name my emotions, but mostly made me feel worse about myself as told me off weekly for things I did that were ASD things, but at the time I was undiagnosed. I was encouraged to come off them by my therapist, since I had got better with people stuff and could stand up for myself.

In late 2008 I came off them following doctors standard taper. 2009 I had very weird symptoms and panic attacks. However as we had a family crisis that year I put it all down to that. I had my heart checked as it felt fast and off, all tests normal. My digestion worsened, I had flu like symptoms, unexplained fears, didn't want to be left alone, etc etc. Many times I went back to my GP and a couple of times I actually asked to be put back on the antidepressants. This was completely out of character. He wouldn't let me, said it was just a "blip."

2010 family crisis over, weird symptoms continued and pain increased. I was (mis-) diagnosed with fibromyalgia and put back on SSRI antidepressants.

2011 I start seeing a private psychiatrist (who also acts as therapist) and was able to talk about cause of panic attacks so wanted off antidepressants. He diagnosed me as autistic and let me know I could talk to him about the original cause of the panic attacks (school bullying) so in 2012 March I came off SSRI antidepressants again following doctors standard taper again. My psychiatrist was very ill, so I got my GP to help me come off them. He used standard taper.

For a couple of months I was fine but felt weird, then I started having daily waking panic attacks, this continues for 8 months at least.

Since then, I believe I've been experiencing SSRI antidepressants withdrawal. I believe I was experiencing SSRI antidepressants withdrawal 2009-10 as well, as the symptoms I experienced then are same as what I'm still experiencing now. I've developed many food intolerances, tinnitus, agoraphobia, dizziness, whole insides shaking, itchiness, body burning pains, migraines, lost weight, can't control body

temperature, pressure pains, throat swelling feeling, pulsing sensations, supercharged feeling, so many symptoms...they change and that scares me...

Symptoms are not only physical, are both mental and emotional as well. My emotions huge, memory affected (im a linguist, all my languages have been affected), feel like on verge of panic attack all the time. It's awful.

I'm so angry this has happened to me. I've lost more than my health.

My psychiatrist won't listen to me talk about it, my GP (who I blame most for not giving me enough information about the meds so I could make an informed decision whether to take them, and misdiagnosing withdrawal symptoms as fibromyalgia and putting me back on the meds after almost 2 years off) won't listen either. I get so angry. My GP says its return of original problems and i should speak to my psychiatrist. I know my own anxiety levels, and this is in no way a return of them, its frankly insulting to be brushed off like this. No-one understands how hard this is for me, nor how badly it has affected me. My psychiatrist says I'm a rare case, but online there's many others who are experiencing SSRI antidepressants withdrawalthough most have healed in less than 6 years.

I'm exhausted emotionally and physically. Every day I have to convince myself I'm ok when I'm clearly not.

I don't trust doctors now. I can't. I have so many misdiagnoses and misinformation from them. Over the years I've tried many times to show my psychiatrist academic articles and books about SSRI antidepressants withdrawal, he doesn't seem interested and to my knowledge, didn't read. I've also written twice to my GP and printed articles off to show him. His response would indicate he hasn't read and doesn't care. He just repeated "withdrawal lasts 3 months and this is return of original problems."

2018, Now my psychiatrist won't see me or support me anymore. He stopped direct email support and cancelled all my appointments. Unless I find a co-therapist I can't have another appointment. He says I use him as a metaphorical punch bag when I get angry, but I only get angry because he doesn't want to listen to withdrawal stuff and wants me to concentrate on diet and histamine stuff. He thinks I have mast cell activation syndrome and EDS, but to me it's all withdrawal. When I gives me diagnosis of MCAS etc, and tells me to concentrate on diet, it's like he's blaming me for every time my symptoms worsen, but I can eat clean and still feel absolutely awful. Over the years he's suggested many supplements that he thinks I should try, I've tried some, but my body is so sensitive and I'm so scared of making things worse, I don't want to try much. Most things I've tried have made symptoms worsen. So the medical profession caused this illness, now washes their hands of me because I won't accept another misdiagnosis. This is appalling. I've probably read far more articles and have more knowledge of SSRI antidepressants withdrawal than either my GP or my ex-psychiatrist/therapist, yet they chose to not listen. Its like my 6+ years of hellish symptoms doesn't matter to them.

I need support with the changing symptoms and huge anxiety. Though finding anyone professional to support me is impossible, so I'm reliant on the Samartitans

and online forums. I blame the media and Royal College Psychiatry and GPs for the lack of support available and believe that they deny that SSRI antidepressants withdrawal can last this long and make it sound as if it is short lived and merely "unpleasant."

My life now is in 2 parts, pre-meds and post-meds. It's changed so much. Pre-meds, my anxiety/panic attacks used to be situational only, post-meds I'm on the verge of a panic attack all the time.

Pre-meds I could plan to do things, travel, meet friends, take opportunities. Post-meds I can't plan to do anything as don't know what state I'll wake up in. 3 of my foreign friends have spent time in the UK during these 6 years, and I've been unable to meet any of them. I've not left the country once since this nightmare started. For the years 2-4 I forced myself to go out for daily walks around the local shops, and weekly car trips with my mum. I gradually built up the distance and time spent out of the house. But unlike normal anxiety where the more you do something, the easier it gets, withdrawal anxiety just carry on and never stops. It was so frustrating and exhausting so I stopped. And I had a huge panic attack in the car in 2016, and couldn't face other trips after that. I'm pretty much housebound now. I don't want to force myself out and make things worse for myself. Lots of times when I was outside I thought I'd faint and got really really scared.

Pre-meds I thought of suicide about twice, post-meds I swing between being so scared I think I'm going to die, and being so scared I want to die, and thinking of ways I could die.

Pre-meds, I wasn't 100% healthy, but I knew how my body/mind would react in situations. Post-meds I've lost trust in my body as I don't know what state I'll wake up in,

Pre-meds, I naively thought the medical profession were there to help us, and trusted them unquestioningly. Post-meds, I've lost trust in the medical profession as I know it is the meds that caused this. I've also had so many misdiagnoses, I'd rather be my own doctor now. This is an iatrogenic illness.

Pre-meds, I had things I needed to solve (bullying), but had confidence I could do the things I wanted to do (live and work in Asia, travel around Asia), and make decisions by myself. Post-meds, my self confidence is so low and I second guess myself often. I hate who I've become.

Pre-meds, though not entirely comfortable, I could take buses, trains, planes, underground systems on my own. I liked to know the exact route and stops, so I could tick them off, as it reassured me. I was fine in cars. I was learning to drive, and had passed the theory test easily, was preparing for the practical. Post-meds I'm too scared to go out on my own to use public transport. Even cars are a problem. My theory test that I passed has expired. I don't know if I could trust myself behind the wheel of a car with my current symptoms.

Pre-meds I couldn't name my emotions, and I buried them. Post-meds all my emotions are huge, super sensitive and scary. I'm agitated, irritated, mood swings,

just cry, with only small or no stimuli. I just wake up that way. They, and my symptoms overwhelm me.

Pre-meds, I was lucky enough to be able to live and study in Japan for a year as part of my degree, teach English in China one summer, travel to Hong Kong, Macau, Iceland, Austria, Portugal, Belgium, Japan, around the U.K. either independently or with friends. I used to like to travel and dreamed of living and working in Asia. Many of my friends are Asian. Post-meds, now I can barely leave the house. Some days i just stay in bed. It's the most comfortable place.

Pre-meds, my relationship with family members wasn't great, as I always struggled socially, but I had relationships with them and could talk to them. Post-meds, Withdrawal has caused relationship difficulties because they believe the mainstream media saying ssris are safe and can't understand how I can still be so ill when the meds are out of my system. They think I'm not trying hard enough to help myself, and am "finding stuff online and thinking you have it," almost like I'm making it up. I can't find the words to tell them all the symptoms I have, so they don't understand how hard this has been for me, and continues to be. If i have a panic attack at home I'm told off then ignored by all at home.

Pre-meds I used to be able to concentrate on one thing for hours and hours. I used to be able to "see" Chinese characters in my head, so if you said "Cherry blossoms," I'd see 櫻

Post-meds. I can't see characters in my head now, nor can I concentrate on things for very long. It's like I've lost my autistic superpower, the one good thing about my autism. Chinese characters are used/have influenced many South East Asian languages, so inability to remember/picture them is a huge thing for me. My memory has been affected, both short and long term. I can't concentrate on anything for long, it's like my brain is supercharged still. My languages are decreasing through lack of use. I use learning languages apps as distractions, but this hurts as well as helps, as I don't know when or if I'll be able to travel again.

Pre-meds I had digestive issues most likely from IBS symptoms caused by unknown intolerances to gluten and dairy. Post-meds I've developed intolerances to soy, nut, histamine, sugars. If I don't take my probiotics it's like my digestion stops and I can feel the food going down very very slowly and uncomfortably after eating. Other times i get full very quickly, other times I have no appetite, big appetite. Even if I eat "clean" I'm still overwhelmed with many symptoms. Sometimes I wonder why I bother.

Pre-meds I've used to play badminton regularly, run twice a week, enter competitions and races. I ran Great South Run twice, did many 10km and 5km races.

Post-meds I'm housebound and unable to exercise as it exacerbates my symptoms. I've also lost too much weight and am scared I'd faint if I played badminton now. I've lost friends as I can't meet up with them and do things with them.

Pre-meds i could apply for jobs, and have chances of getting them. Post-meds I have a huge hole in my CV now as I'm too ill too work, I'm on benefits, which is

added stress due to government policies

Pre-meds I was sensitive, post-meds I'm many times more sensitive to the point that certain smells now cause migraines.

Pre-meds I'd get stomach pain, upper back pain and pain from sports injuries. I was used to all that. Post-meds I'm in pain most days, all different types of pain, different places, pain that moves, pain that increases with stress, pain that makes me want to cry. I'm not used to it, because it changes so much. I put up with it for a while, then can't any more.

Pre-meds I'd say I ate pretty healthily (always over 5 fruit/veg a day, no red meat) and was (For me) a healthy weight (7.5~8 stone). Post-meds, my weight has dropped a lot and I currently can't put weight on, can lose it very quickly though. And I have so many intolerances that I have little variety in my diet and am probably not getting enough vitamins/minerals.

I didn't need the meds in the first place. I needed validation of my experiences and emotions that caused the panic attacks to start when I was 14. I needed to be diagnosed as ASD and taught social skills and emotions management. And I needed my confidence built up.

I think normal human emotions are being medicalised unnecessarily. I was being badly bullied at school and the panic attacks started when the bullying changed and they started threatening to kill me or beat me up. Becoming scared is a natural human reaction to this.

I want to get well, I want to have a life again. I don't know if it's possible. I want this to never have to happen to anyone else, financial and emotional support to be made available to people who are currently going through it. Doctors need to be held accountable for their actions and be forced to disclose all they know about meds before offering them to patients so that true informed consent is gained, meds to be used as absolute last resort, and pharmaceutical companies to have to show all their data and not hide any about negative effects of their meds. I also think doctors should be trained in nutrition. I think I should be compensated for the loss of health and way of life.