

PE1651/AAA

Jo Dennison submission of 31 December 2017

At age 17 I was low in confidence, after 16 years of trying to withdraw from antidepressants, my life is now intolerable. I am 34 years old.

I was improperly prescribed an SSRI for low confidence at my first job at age 17. I know now that this SSRI is not recommended for people under 25 as the brain is not fully developed. I was kept on it for at least a year before I thought that I should try and come off. I never had depression before being given this drug. Every time I tried to come off I would be back to my normal self for two months then I would hit severe depression, a feeling that my brain was stopping and starting, severe anxiety so that I couldn't function at all, adrenaline rushes that would continually wake me through the night and agoraphobia. I felt so terrible on the drugs, numb and disinterested in life, so I kept trying to come off them only to be completely dysfunctional and much worse than when I started these drugs. It took me sixteen years to realise what was happening - I was going in and out of delayed withdrawal and the anxiety and depression was the result of withdrawal similar to that which people experience in illegal drug addiction but I was in this condition because of going to the doctor!!! And it seems my doctors had no idea what was happening either.

And so after 16 years, I joined withdrawal support forums and found that there are many hundreds of people worldwide that are experiencing the same things and they are the people that realise it is the drugs. How many more have no idea it is the drugs that are making them so ill? I couldn't get stable when I went back on the drug and I was struggling with severe anxiety while tapering small amounts. The online support groups suggested not to switch drugs as it could get worse but I had assumed it couldn't get any worse, as I still could not go back to work and I couldn't get stable back on the drug nor reduce even tiny amounts. I did not know that what was happening to me was even possible as a result of taking an antidepressant drug.

I took the terrible decision to go back to the psychiatrist who then decided to stop the SSRI I was on and switch it to Prozac which is meant to be easier to come off. She did this over two days only. I felt a bit better on Prozac for a month or so and then I felt something terrible happening in my brain. I was terrified of withdrawal so I tried to still come down slowly but I also felt that I was maybe doing more damage staying on it. And of course, even on the withdrawal online support groups the reaction I had seems so rare the advice was still to reduce slowly and of course the psychiatrist denied that anything was wrong at all and it was just side effects that would subside once off but of course she also does not recognise severe long lasting withdrawal. The adverse reaction I had isn't recognised or believed by the medical profession. **So just to recap, I went through sixteen years of going in and out of drug withdrawal and being severely suicidal. And what has happened since is even worse.** I have now been off all SSRIs for two years and two months and I've actually worsened in time. The feeling is that my brain is absolutely starving of oxygen, I know in neurotoxicity this is low blood flow in the brain. Why am I unable to access any appropriate tests on the NHS to identify what is wrong?

I am now experiencing something so inhumane that it is much much worse than suicidal depression and every day for two years now I scream that I cannot live with this. I have found a few people that have experienced what I am experiencing and it has been confirmed that they have neurotoxic brain damage via SPECT scans, assessed by an expert in neurotoxicology. It has also shown up in PET scans. A few people have had what is

called q-eeg testing (1) and the results suggest that the brain is functioning as in traumatic brain injury.

I cannot get the NHS to do the tests that would confirm such damage in my case. Why is this? Perhaps the NHS prefers that we do not have access to appropriate tests for fear of what the results might show. My psychiatrist's response is that this could have happened anyway. There is no way what has happened in my brain could have happened anyway. I can say with absolute certainty there is no anxiety or depression that could ever be as bad as this. I do not understand why the doctors do not understand that the chronic depression I am now experiencing is completely different and so much worse than the sort of depression where you can find the root cause and work through it.

I am only 34 years old and feel my life is absolutely ruined. On the second drug I was switched to I heard a frying sound in the right side of brain and ever since then it feels like I have had a modern day lobotomy. It is as if my brain can only see and hear life around me but can't experience it. For two years except occasional breaks there is no sense that there is any life here, no sense of existence, no sense of family existing. The front of my brain feels like there is a vacuum and nothing there. The psychiatrist said that she has heard of many people with depression and anxiety describe strange sensations in their head. This is ludicrous, what I am experiencing is far beyond "strange sensations".

The fact is the NHS website states that they don't really know how these drugs work. They work on the neurotransmitters and then when people are desperately harmed they deny it, patronise us, laugh at us. I know from people who have been able to consult private specialists that this vacuum feeling is either nerve damage or low blood flow to the brain. It feels like my brain is suffocating and struggling every minute and is absolute agony to do anything. Cleaning is agony, trying to do simple mental tasks is agony, just being alive and awake in this horrific state is agony, I haven't had even a minute that has been bearable for two months now. The condition has gotten worse in time.

I cannot distract myself from this terrible condition because there is nothing to distract myself with. I try and do things I used to enjoy but there is no joy in anything. There is not even the perception that any activity is taking place. To add insult to injury no one believes that what I am experiencing is in fact a neurological condition. Yes, it is true that loss of interest in things can be depression. However, loss of interest and ability to feel emotions and perceive life normally can also be as a result of frontal lobe damage. These drugs work on neurotransmitters that is the same part of brain that cocaine and ecstasy work on. It is accepted that these illegal drugs can do long term damage even though it may not show on tests such as MRI scans. I really do not think that most doctors understand the toxic effects of SSRI antidepressants. The effect on the neurotransmitters are not fully understood but they do know that the neurotransmitters are involved in many functions and they also allow communication between different parts of the brain.

In the few times that I was off the drugs over the years and before the second devastating reaction, I was interested in so many things, wanted to learn so much and do so much. Now I can hardly do anything. I had to give up work, even one day a week volunteer job, no social life, absolutely nothing. Doctors seem to deny the fact that some people are permanently damaged by these drugs. Most psychiatrists and doctors have said that they think my condition is "all psychological". Even if I had had no confirmation that the drug had done this I would still know it beyond any doubt whatsoever. There is nothing more maddening than being told it is a psychological condition when you know something neurological has happened. I was referred to Prof David Healy, Bangor, Wales by my local health board. He confirmed that the drug has done this and even after this the psychi-

atrist and GP said they "think" it is psychological. They disagreed with Prof David Healy but they will not give me any more drugs because that is what he has recommended. I quote the psychiatrist when she said "we don't want to give more drugs because we do not want to do you more damage" before adding "but I think it is psychological". The GP even shouted at me that the burning acid in my head and terrible head symptoms that I never suffered from before the second drug is all psychological. It seems that to challenge them about the drugs that they only vaguely know how works gets a response that is highly defensive.

I get occasional relief from Valium which they will only give three times a month because "they are highly addictive". I have reminded doctors that in the past they have prescribed Valium for the same things as antidepressants and history is just repeating itself. I have told my psychiatrist that she will be responsible for my death and the devastation it will bring on family. The response to this was "it wasn't my fault, it was the psychiatrist before me that looked up the INTERNET who read that to come off one SSRI you could switch to Prozac". No apology, remorse or concern - just passing the blame onto someone else. There are a few of us that seem to have a total shutdown of the part of brain that would be able to process life into a meaningful experience. We know someone that is in a similar state from being damaged by a drunk driver. But unlike them we will receive no apology, validation, treatment or understanding and the people responsible, the drug companies and medical profession, they will never be held accountable.

What needs to happen?

A telephone support line is too late for those of us who are severely damaged. There are many reports online of people taking these drugs for work stress, even just one or two pills, and losing all human emotion and still like this fifteen years later and never able to work again. I do not understand why there seems to be no official reports of this as my psychiatrist said she has never heard of this. We are human beings not things to be experimented on. Is it also ok that I cannot endure much more and my whole family suffers as a result? I had a lot of potential now I cannot even do a cleaning job. The symptoms change wildly every hour and is completely unliveable. I just barely survived a Christmas like this and I doubt I will survive another. At 34!! I may die fifty years too early because I went to the doctor because I had low confidence at age 17. This is no reason to be damaged so terribly by doctors.

It is really important that inappropriate prescribing is addressed. The questionnaire, PHQ-9 that doctors use to help them identify depression was produced in collaboration with the drug company, Pfizer. (2) It asks if you have felt consistently low for a period of two weeks or more and therefore sets a low bar for assessment of depression. I know that Prof David Healy has said that many people recover from severe depression naturally over 6-9 months and so it seems that improper prescribing of SSRIs has created an epidemic of disability and long term chronic depression, as documented by Whitaker.(3) He has also reported that in many countries, including the UK, as antidepressant prescribing rises so too does the number of mental health disability claims.

(1) <https://www.121neurofeedback.com/brainhealth-qeeg-info/>

(2) <https://patient.info/doctor/patient-health-questionnaire-phq-9>

(3) Whitaker R (2011) Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America.