

**PE1651/YYYYYY**

Anonymous submission of 11 February 2018

I live in Essex uk and am a 33 year old female with 2 children and a long term bf with a great job

In October 2013 I gave birth to my daughter and after a couple of months with lack of sleep due to her having acid reflux - I went to a&e with dizziness which I now know was purely exhaustion

I was given prochlorperazine and after one tablet had a catastrophic reaction called akathisia and was instantly suicidal

I was told I had post natal depression and put on Prozac the next day and had another catastrophic reaction - I momentarily lost my vision and collapsed - this was one day after taking it

I stopped both drugs and was suffering insomnia , feeling utterly suicidal , I could not sit still , think straight or even talk, it felt as tho my skin was crawling and I had an electric current running thru my veins- I had NEVER felt any of these feeling before in my life.

I later discovered that prochlorperazine is a first generation 1950s antipsychotic drug which isn't even used on psych wards anymore due to the side effects I was very lucky that I didn't get dystonia as this is permanent and I know many who are now disabled for life from this one medication! His can this be legal???????

Akathisia is the WORST feeling that a human can possibly feel and most people take their lives because of it It happens wen people either start taking psychiatric drugs such as anti psychotics, anti emetics, anti depressants , anti anxiety drugs such as benzodiazepines Or when people either up or lower their dose or when they come off the drug wether they taper or cold turkey .

I tried to carry on but a month later I decided I was going to take my life - the Doctors put me back on an Ssri- sertraline

I had another reaction feeling like I was being stung all over by bees including in my skull and eyeballs

I then tried to lower my dose from 100 to 75mg and the akathisia and all the other symptoms got worse and I ended up in a psych ward for 3 days- what a disgraceful place and disgraceful staff and Doctors - I was constantly told that I was doing this to myself and that I needed to stay on the poison for life!

Every time I took it I felt worse so I tapered off over a year The less I took the Better I felt and by the time I was off I felt about 90% Better

Sadly 4 months later I hit acute withdrawal and over night got hit with over 50 debilitating symptoms and the akathisia worse than ever Severe dizziness ( a different level to what it First was ) Severe vision issues, blind spots, Misty vision,

floaters , things appearing larger or smaller than they are, things appearing in my vision that look like small dots, trailers and acid trippy looking vision, weakness, fatigue, anger, flu like symptoms, hearing issues, constant tinnitus, burning and tingling and numb patches of skin, breathing issues, confusion, memory loss, fear, panic , chemical anxiety and severe black depression - and so much more- but the worst still akathisia.

I am now 30 months off the medication and most days still feel suicidal

I have been unable to work for 4 years, had to cancel my wedding and worst of all have missed the first 4 years of my daughters life and my son who was 6 at the time is now almost a teenager

Words cannot describe the utter hell , torment and terror that I have lived thru and continue to battle thru every single day and not one ounce of help, empathy or sympathy from any doctor

The hell that my family have and still are going thru due to this is indescribable and things need to change

There needs to be research and a cure found for this hell

Can i please also quickly ask why people use the word “dependence”? I really need to strongly point out that I was never dependent on any of these drugs , the same as most of us in this terrible state I had a “ reaction” to the prochlorperazine drug and then to the antidepressants.

I was told to stay on the side my entire life but only stayed on it for 6 months as every time I took it I literally felt it poisoning me .

My body then couldn't adapt to the changes when I withdrew from it which took me 12 months!

I and the majority of others who have this brain damage from drugs such as ssris and benzos never even liked the feeling of being on them and never craved for them - it is just impossible to stop taking them and feel ok for some of us for some unknown reason which is something that desperately needs funding and looking into.

I would love to see the word “ dependence “ taken out of this entire scenario as it is quite the opposite - we have brain and central nervous system damage from a prescribed medication from our Doctors and not a dependence withdrawal like an alcoholic or a drug addict would have if that makes sense?

It really does imply that we are the ones who have done this to ourselves and have some kind of dirty habit when as I said we never craved or enjoy the drug, we couldn't wait to get off of it and have never wanted it again ,so very very opposite to someone who is “dependant” on alcohol or illegal drugs and I really feel that this point should be addressed as it is not us patients who are the guilty party , it is the Doctors and pharmaceutical companies - we are very much the victim in all of this - simply because we trusted our Doctors.

This is absolutely the worst kind of illness as the intensity of the symptoms is so beyond horrendous and that is why so many people take their own lives- I have known athletes, Doctors, young mums and dads, all walks of life who have taken their lives due to these drugs.

For the ones who don't take their lives like myself , we have been left to fight with every ounce of determination that a human can have , but not just for a few hours or days , but for some of us this can and has gone on for years and years and the worst thing is that none of us know how long it's going to last - the duration is unbelievable for most of us .

For personally I have fought for over 1500 days and nights now - that's 4 birthdays ( soon to be 5 ) and 4 Christmas' totally ruined where I have had to be by myself and suffering in my bedroom whilst the rest of the world have been enjoying themselves with their loved ones.

4 of my sons birthdays and 4 of my daughters birthdays that I have not been able to join in with the celebrations , being unable to do anything with my children or family, no holidays, no helping out up the school like other mums do - absolutely nothing and this is the same for everyone who is affected by these drugs.

Recently I have managed to go for a couple of days out with my family but nothing has been fun or easy- I have smiled for a photo but my family have seen me crying where I'm in such a bad way enveloped in horrific symptoms.

I have been unable to work up until 2 months ago and still can only work for 1-2 hours a couple of days a week from home , I have come close to losing our home, my relationship with my partner ( who I should be married to but we had to cancel our 250 person wedding and lost thousands of pounds )is barely surviving , my children have as a shadow of a mum for over 4 years now , many of my friends I no longer hear from as I have not been able to function on any level and I still have a very very long way to go yet-

And what do we get for it? ZERO help from Doctors, ZERO help from councillors unless you are lucky enough to find one who understands these drugs which is very rare and ZERO help from many friends or family ( thankfully my parents have been amazing ) as there is absolutely no awareness of this whatsoever and people literally think we are mad but most appallingly of all, we get laughed at and belittled by Doctors , the very people who put us on these poisons in the first place.

I have tried to sue to claim back some of the thousands of pounds that I am in debt for now but apparently it's just tough luck as some people are fine with the drugs?

What about those of us who aren't?

They don't even fully understand how these drugs work in our brains but we are disbelieved when we have an adverse reaction or a withdrawal reaction?

As I said this isn't a bad reaction for a day, week or month, this is YEARS of sheer hell that we endure and not even any recognition by the medical " profession " !??

I just would like to add that in almost every case of shootings, murders and suicide the person involved was taking some kind of psych med but the dots are never linked together!?

How is any of this possible?

It's possible because the pharmaceutical companies fund medical schools and never tell Doctors or patients of the possible reactions to these drugs and therefore there is disbelief and zero awareness - this all needs to change and there also **NEEDS TO BE FUNDING TO FIND A CURE OR A REVERSAL FOR THIS BRAIN DAMAGE** because every second of every day and night there are people contemplating taking their own lives and this cannot go on any longer !

The **BARE MINIMUM** that we deserve is support and acknowledgement from Doctors to help us through these years of loss and hell.