

PE1651/K

Ann Kelly submission of 21 June 2017

I was first prescribed antidepressants around the age of 15. I met with Shona Robison MSP, Cabinet Secretary for Health and Sport on 26 October 2016. I explained my personal account of prescribed drug dependence and withdrawal to her, which is annexed below.

The Cabinet Secretary provided a written response to me as a result of the meeting in Holyrood, which suggested going back to my doctor.

I went back to my doctor and his response to me was that in the course of his work, he sees a great many people who live miserable lives, but they just get on with it!

When I showed him the Cabinet Secretary's written response with specific terms highlighted that suggested that positive outcomes were possible...he said that the contents of this letter were not relevant to my individual healthcare! He said words to the effect of "the problem with someone like you is"... and I stopped him there because it should not be about me personally. I was expecting him to focus on specific medical issues that warrant exploration and investigation. What I got was a subtle attack on my personality and who I am as a human being in the hope that I will carry the burden for what is a medical problem. It's abundantly clear to me that once someone allows a mind altering drug to be administered they forfeit the right to chemical stability within their body with the result that they are forever 'chasing wellness' much to the irritation of GPs.

I know he will confirm this. He couldn't really deny it because my sister was with me on both occasions. (I never... but NEVER... go to any GP surgery on my own!)

Another relevant point is that as a result of the multiple severe disabilities that I have and am enduring, through sheer desperation, I went to a private clinic in London who practices functional medicine hoping for a positive outcome. She made an error of judgement and injected me with histamine as part of a therapy. It further damaged my autonomic nervous system which I have recorded by the clinic as part of an Autonomic report. I was in accident and emergency at least 3 times on my return from London.

In spite of this when I asked my local GP to test me for histamine levels, he told me it was not necessary. If someone presented with their body flooded with drugs either recreational or prescription, you would think that whatever substance(s) is present in their body, should be relevant, but apparently it wasn't! When I asked him why he wouldn't test, all he would say is "I don't think it's relevant".

I have raised concerns that I have suffered brain damage to the myelin sheath which is the fatty protective covering that insulates the nerves (my concerns have been repeatedly dismissed).

Annexe –

"Rebellion" is when you look society in the face and say "I understand who you want me to be, but I'm going to show you who I actually am"...

My father died when I was 14. Shortly after this, our 16 year old beloved family dog died in front of me without any chemical euthanasia while I was in the house alone. It took about an hour for him to die. I was transfixed yet traumatised at the same time. A year and a half later, I split with my childhood sweetheart who I'd been with for 2 years....so I was a teenager... hormonal... with a sensitive disposition.....There is no record of ANY of this in my medical notes yet my memories of this time are vivid.. The next 30 years were spent numb, insulated but functional, other than when I forgot/stopped/or tapered the drug.

I had relationships, but my connection was not a proper connection on which you could build a future.

I held down jobs but my involvement in my work and with colleagues was not truly authentic. By my middle thirties, I had a strong sense that I wasn't living my life correctly, that I wasn't guided from the seat of my own emotions...

I'd often experience an odd sensation that I now know to be derealization and depersonalization. I felt like a fraud who was wearing a mask... too protected ... and way too insulated to connect properly with life!

I was "hard" ... disconnected and thoughtless towards other people. I had no desire to bond properly.

Looking back, I was chemically tweaked and recalibrated... as opposed to now, where my mind is very clear.

At the age of 46, I decided to taper the drug Venlafaxine. I researched and realized it would be difficult, and so I tapered the drug slowly over two and a half years.

My entire universe collapsed in on top of me. My life, my relationships, my finances, and my capacity to take care of myself has been reduced to a barren wasteland.

I have many restrictions on what I can eat: No sugar, white bread, alcohol, processed food or pasta.

Chemical sensitivity is a huge issue with me but I don't have the time to expand on this for now...

Since tapering in 2008.... my life has read like a Steven King Novel. My symptoms have been merciless and unendurable.

I'll start from the head and work my way down.

Inside my skull... there is a Burning, crushing, stinging, numb, sensation. It feels like car battery acid is being poured through my skull. Alongside this...my cognitive functioning is compromised. I struggle to do simple tasks... shopping cooking, coraling my thoughts, completing tasks, bathing, sometimes I struggle to get food from the plate to my mouth... basic household chores are a thing of the past.... no ironing, cleaning windows, cutting grass, the normal stuff that makes up a life. I cannot learn new skills and process new information...These are the things that make up a life well lived...proof if it was ever needed that my life has been taken from me...

My Eyes?...Well...having been repeatedly told by my local NHS optician that there was nothing wrong with my eyes, a hard won (and somewhat begrudged) appointment at Gartnavel revealed on an electroretinogram test a "minor abnormality".

This result did not even BEGIN to explain the devastation that I am experiencing. So a recent test by Ian Jordan (the ONE person in Scotland who could test for sensory processing) revealed I have Major visual disturbance. Not in one area, but in at least 12 areas. Many of these disturbances I am unable to describe. However...Apart from the hours I sleep, I experience Foggy Vision, pain moving my eyes, from side to side, and from near to far, bright sunlight is unendurable, a time lapse or lag when moving my eyes in any direction, poor peripheral vision so I fall over things, am clumsy, uncoordinated, trip over my dog, stagger, have balance issues, can't even scroll text on my phone or laptop without experiencing a dizzy sensation... when I blow my nose, I lose my

balance.... I won't go out or do anything that involves moving my head or eyes. (and that rules out pretty much every activity in the known universe)...again proof if ever it was needed....

Joint Issues....My joints are achy and stiff and they burn and are tight, it feels like they have no lubrication, and there is a weakness in my efforts to move around. I believe I could have premature muscle wastage/early osteoporosis/arthritis or some combination of these. Getting up from a sitting position I move like someone twenty years older than me. I won't even go into the bladder and gut issues I have.

Memory issues... my short term memory is totally shot, and I have flooded the caravan costing 5K of damage, and I've almost set it on fire, came close to killing my two beautiful Bernese Mountain Dogs when I left a pan on the stove and forgot about it. The memory of seeing them cowering in the corner of a smoke filled room is something that will live with me forever. I have accused someone of taking a significant amount of money, only to find that I'd placed the money elsewhere and forgotten... the resultant trauma of that was totally devastating...I've missed countless appointments, including doctor's appointments, for which I've been warned by the practice that if it continues, I would be asked to leave the practice.

Psychological issues... I have had suicidal thoughts for the last six years. I've said this before, and I'll say it again... NO HUMAN BEING SHOULD EVER HAVE TO TOUCH ANYTHING THIS BLACK. To mess with people's neurochemistry and create a chemical "storm" inside their bodies should mean accountability... looking at the way my circumstances have been dealt with....it doesn't appear to! In fact quite the opposite... I'd like my sister to read an account to you about the ways in which I was treated by my GP practice)....

My relationship with my ex-partner ...For a relationship to function well, you need to be operating naturally and authentically for it to even stand a chance. For the last 8 years, I have endured a distorted reality where my nervous system is hyper vigilant and super sensitive. How can a relationship stand up to someone whose up screaming and crying in the night, suicidal, clingy, needy, and unable to take care of their partner. My ex-partner is a decent bloke who was trying to make sense of this nightmare. Needless to say, our relationship lies as part of the wreckage from this "chemical train crash" that I've had to endure.

Neurological issues... I've had ice packs strapped to my head for the last 6 years... (Day and night). It's beyond me to find words to describe the merciless crushing pain, and the numb tingling sensations, the thick foginess in my head that feels like my brain has been sliced and put into a hot fryer and then put back into my skull. This results in distress and confusion that I endure until I fall asleep.

After asking twice to see the neurologist, she told me she has seen these symptoms before, but she didn't know what they were???? Then, years later when I asked to see her again, given the severity of the symptoms, she sent a letter to say they wouldn't see me because they didn't see a point !!!

I put this letter alongside the letter I got from the psychiatrist, who said pretty much the same thing, when I asked if they could get involved in this given psych drugs caused it. They too refused.... Wonder why?...

I had an appointment with Professor David Healy in early 2013. A subsequent meeting was held in Dumbarton in 2013 in which Professor Healy participated by phone and others were present. Jackie Baillie MSP summed up in the minutes: "It was acknowledged that Ann was suffering from withdrawal from antidepressant drugs. Her condition was not, and is not, a personality disorder but is a chemical reaction to the prolonged prescribing of drugs on the advice of medical professionals." The minutes can be provided if necessary. This clearly states that my multiple severe disabilities (Work and Pension terminology) and chronic long term health condition is

directly attributable to ADs. Ian Jordan's letter is clearly stating that there is damage done to my vision. He has said he has seen these symptoms before but only in people who have suffered a brain injury. (I'd like to just leave that statement hanging there for a minute) I have had no traumatic brain injury other than the 8 year trauma and disablement I've been given as a result of antidepressants. He agreed with me that my problems are definitely not developmental. He suggested strongly that I look to the Brakespear Clinic in the first instance. Another psychiatrist has stated in his letter he believes my problems are physical in origin, also that he does not believe I have any kind of personality disorder as was given to me while in a state of acute withdrawal from the psychiatrist.

Just to recap....Fourteen years old, sensitive disposition, two or three traumatic life events and then drugged with 161,280 mg of Fluoxetine, 453,600mg Venlafaxine and many more other antidepressants. At this point I'd really like if you could pause and reflect on whether there could be a morality issue here?

I'm not someone whose body can't metabolise the drug, and has had a violently chaotic and psychotic reaction. In a case like that, they are fortunate ones, in that they have dodged a great bit bullet... Nope... I represent the majority of the people whose body has taken the drug, and has worked dutifully with it for a very long time. (That will be the 1 in 5 people in Scotland who take an antidepressant). Often I would reach tolerance and again, believing that the disturbing symptoms were my original illness. So again, I faithfully take another stronger drug, or higher dose of the existing drug because I'm told to. My multiple severe disabilities and chronic long term health condition mean that I am now living off this state and unable to reach my potential. How can more drugs possibly be the answer to the problems I have been given?

HOW MANY INACCURACIES CAN YOU HEAR IN THIS NEXT PARAGRAPH...?

How dare ANY human being take someone who is physically well, (temporarily overwhelmed perhaps, and in need of support), tell them they have a NEUROLOGICAL IMBALANCE and that they lack enough serotonin (a theory that is based on fresh air by the way)...Tell them they NEED these drugs ... Tell them that the drugs are NOT PROBLEMATIC...then in acute withdrawal diagnose them with a PERSONALITY DISORDER. Then tell them that the multiple severe disabilities that contribute to their suicidality is their OWN ORIGINAL CONDITION. THEN LEAVE THEM UNABLE TO WORK, UNABLE TO TAKE CARE OF THEMSELVES, AND TO FOSTER PROPER LONG TERM RELATIONSHIPS AND TO GENERALLY DECOMPOSE IN THE LONG GRASS.... possibly taking their life as a consequence... (then taint their memory by saying "well ... they did have a mental illness after all!) I counted about Five..... My truth does not sit well with the core beliefs of psychiatry....

I take responsibility for walking into the doctor's surgery
I also take responsibility for initially trusting in my GP
I even take responsibility for putting the tablet into my mouth (Because that action was based on my underlying trust!)

What I WONT take responsibility for, is the resultant damage for coming off a drug that says in the patient information leaflet you will suffer 6 weeks of discomfort. This is clearly not withdrawal anymore – this is damage. Not only that, this is damage that is being ignored and suppressed. I want to make the point that my suffering has been endured considerably longer than 6 weeks, and that my severe disabilities have almost lasted a decade. So I am asking the question?...Is this "withdrawal" or "damage"? If it is "damage"... it needs fixing. In no other area of society would anyone get away with this.

Neither will I accept that my multiple severe disabilities, and chronic long term health condition is one I have brought about myself.

I firmly believe without a shadow of a doubt that the psychiatrist's assessment of Involuntary Iatrogenic Dependency totally explains the chequered and "deeply complex" medical history my healthcare has taken. (My doctor used the term deeply complex referring to my health history while I was in deep acute withdrawal)

Just in case there's anyone left in this room who is thinking that perhaps a little more CBT or maybe another course at the homeopathic hospital could be the way forward? With respect to you, if this is your opinion, ... and it is just an opinion, your perspective on this is based on your belief system that was shaped by your training that was funded largely by drug company money, and NOT on your knowledge of pharmacology. Talking therapies could never BEGIN to make an impact on the crushing symptoms I endure in the name of healthcare.

In spite of all this, my mind is very clear, and my awareness of the situation I'm in is also very clear. Based on the papers I have read, the research that's available, the books, the people I speak with online, and my own traumatic, lived experience, I strongly believe my body and mind has been subjected to a long term sustained chemical attack and that these drugs are brain damaging therapeutics should a person decide for WHATEVER reason to unchain themselves from a drug.

One in 5 people in Scotland take an antidepressant ... So statistically, it's fair to say that at least one person in this room is taking an anti-depressant... and to that person I am saying this.... if you think that stopping this drug is a straightforward option that you have.... think again! ...

I want:

- My situation fully acknowledged for what it actually is: Involuntary Iatrogenic Dependency.
- My health given back to me as a matter of haste. I want what has been taken from me, put back... I want homeostasis returned to my body and my neuro chemistry so that I can live a normal life... which is what I had before I went to a doctor.
- Finance to allow me to be treated initially at the Brakespear clinic, and any other treatments and therapies wherever, whenever, and with whoever; and any associated costs connected to my recovery. (I have spent 30 years of my life numb, 8 years in pain, distress and terror, not to mention financially unproductive ... I don't intend to have to live the last 30 years of my existence with Multiple Severe Disabilities and a long term chronic health condition.
- I want it understood that if stroke victims are given assistance with shopping, walking, rehabilitation, cooking, and various other needs met, then I want mine met too. Along with my benefit reassessed in the fuller light of the disabilities I've been living with for the past 8 years.
- I also want to make clear that if I am asked to leave my doctors practice as a consequence of speaking my truth to power, I intend to make all of this very public very quickly. Your mission statement is to "Do No Harm"... My mission statement is to refuse to be held in this chemically stagnating, isolated, stigmatised, pain filled existence, while healthcare providers remain comfortable. This is my mission statement.... and I will be keeping to mine.

"The purpose of life is not to be happy... It is to be useful, it is to be honourable, to be compassionate, to have it make some difference that you have lived and lived well!" I want to be able to do that. I want this experience to shape my future, where I can be in a position to help people understand the limitations of drugs and to help them make better long term choices... please help me to do that!

The Last Word...

I'm making this submission, a very broken, disabled and traumatised person.... I'd like to finish with a quote that captures perfectly my views on the craft that is responsible for me making this submission....it's by the Author of Alice in Wonderland ... C S Lewis...

Of all the tyrannies, a tyranny sincerely exercised for the good of its victims may be the most oppressive. It would be better to live under robber barons than under the omnipotent moral busybodies.

The robber barons cruelty may sometimes sleep, his cupidity may at some point be satiated, but those who torment us "for our own good" will torment us without end for they do so with the approval of their own conscience. Their very kindness stings with incurable insult.

To be cured against ones will and cured of states that we may not regard as a disease, is to be put on a level with those who have never reached the age of reason, and those who never will.