

## **PE01651/AAAAAAA**

Alison McPartlin submission of 11 February 2018

I am a 51 year old female from Elgin. I am withdrawing from antipsychotic medication that I have taken for almost 30 years. I would like antipsychotics to be included as drugs of dependence and to describe the difficulties I face trying to withdraw in Scotland right now. I highlight the importance of the Highland One-Stop-Shop.

I was diagnosed with schizophrenia in 1990.

In 1990 I was a PhD student at the University of Dundee, newly graduated with a 1<sup>st</sup> Class Honours degree in Biochemistry. I learned a fair amount about drugs then, because the biochemistry department at Dundee was keen to foster links with the pharmaceutical industry (and is now “the world's most influential pharmaceutical research institution”<sup>1</sup>), so I knew there were risks.

Professor Sir Peter Downes, now Principal of Dundee University, gave his inaugural lecture about the drug Lithium – used to treat Bipolar Disorder. When I asked one of his post-docs about the side-effects, I was told: Death.

And yet, I was persuaded (often by force) that the benefits of medication outweighed the risks, that I lacked insight and it was just a matter of finding the right one. After trying about 12 different drugs, I eventually accepted depot injections of **Haloperidol**, marketed under the brand name “Haldol”, a powerful antipsychotic.

Far from enabling me to live a normal life with mental illness, the medication resulted in my dropping out of my studies and becoming severely disabled. I have never worked since, despite numerous attempts, remained single, never had children, never learned how to drive, been the victim of serious sexual assault, still living in short-lease private rented housing. My physical health has deteriorated, and now – as a result of recent cuts in services – I am dependent on my parents for daily support needs.

### **Dependence and long-term harm**

We hear that patients with chronic mental health conditions also have poor physical health and have a life expectancy that is 15-20 years lower than average. Could this be anything to do with the drugs?

Starting in the year 2000, I decided to start keeping a record every time I took medication, the day, time, dose. I was then taking a drug called trifluoperazine, which used to be sold under the brand name Stelazine. I also kept a record of my sleep.

Now, fast forward to 2014. I had been stable-but-disabled on a low dose of meds. I had an autism spectrum diagnosis, social support from the Highland One-Stop-Shop and was now treated only by my GP. Still unable to work, but with a reasonable

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<sup>1</sup> <http://www.bbc.co.uk/news/uk-scotland-tayside-central-41780810>

quality of life. My sleep was a problem and I had taken occasional diazepam over the years, careful not to become addicted, but due to some stress in 2012, I ended up taking diazepam every day and was filling my repeat prescriptions early. By 2014, I realised I needed to stop. I tapered and stopped diazepam over the course of the next year with the help of BenzoBuddies forum. The curious thing was that once I was off the diazepam, I was much less anxious than I had been while on it.

So now I began to question the need for trifluoperazine, the antipsychotic. Was I taking it simply because I had become dependent? Was it doing more harm than good?

Drug dependence means the body has adapted to the drug and involves tolerance, where the drug is no longer so effective at a given dose. Tolerance can occur to some drug effects and not others. Tolerance to unwanted side-effects is a good thing, but tolerance to the desired effects of a drug can result in increasing doses to get the benefit – as Dr John Mitchell pointed out on 18<sup>th</sup> January 2018. So I asked the question, has my drug dose increased over the years?

I looked at my diary data and worked out the average dose each year from 2000 to 2016. There was a gradual, but steady increase in my trifluoperazine dose year on year between from about 4mg in 2000 to 7mg per day by 2015. It was a linear pattern, thus unlikely to be caused by life events which are quite irregular, thus best explained by tolerance and dependence. Because the yearly increase was so small and because I have had different doctors every few years, it just wasn't picked up on.

Over the same time course, despite stable mental health, my sleep has got steadily worse, and poor sleep is associated with poor health. I suspect that symptoms such as chronic poor sleep, due to drug tolerance and dependence, contribute to the poor health of patients with long-term mental health conditions.

The leaflet that comes with this medicine says not to stop suddenly as you may get nausea, vomiting etc – but these are acute discontinuation-type symptoms which will pass in a few weeks. There is no mention of long-term dependence and tolerance. I would like to flag up this issue with anti-psychotics.

### **Withdrawal experiences**

I started tapering trifluoperazine in 2015 following the motto of the internet forum Surviving Anti-depressants: Keep It Slow, Keep It Simple, Keep It Stable.

At each cut, I experienced acute surges of severe acid reflux, vice-like headaches, tight shaky muscles, frequent urination, against a background of sustained, amplified anxiety and easily triggered panic – way above any baseline anxiety I may have.

Fortunately, my GP was supportive. I saw him regularly for reviews. The Highland One-Stop-Shop also provided non-judgemental support - one to one sessions, group social activities, and drop-in space. My parents helped with day-to-day stuff. So I was able to cope. I stopped the diazepam and reduced my anti-psychotic by a third.

Then, catastrophe struck.

First, without warning, in September 2017, trifluoperazine pills were unavailable from the supplier. I was able to get a liquid version for a couple of months before that too ran out. In November, the pharmacy suggested I ask my GP for a substitute. This is part of a larger problem with the supply of generic drugs and relates to pricing<sup>2</sup>

Second, when I tried to get an appointment with my GP – the one I have seen for years – I was shocked to discover he had reduced his hours, and was booked up. This too is part of a larger problem, the shortage of GPs in Scotland, especially in rural areas, highlighted recently in the BBC documentary “The Family Doctors”<sup>3</sup>

So I was in the precarious position of experimenting with random substitute drugs, under the supervision of a GP I'd never met who was acting on telephone advice from a psychiatrist I'd also never met. The substitute drugs didn't work. I was plunged into a nightmare of extreme fear, paranoia, agonising abdominal and chest pains and insomnia. I ended up in A&E thinking I was having a heart attack. Eventually, I was referred to see a psychiatrist in person.

However, while waiting anxiously for my psychiatric appointment – worried I might be misunderstood or forced back on unsuitable medication – I reached out to one-stop-shop only to receive the devastating news that the Highland One-Stop-Shop had lost its funding and faces closure by March 2018<sup>4</sup>.

I cannot emphasise enough what a vital role this service plays in the lives of autistic people in the north of Scotland. Autism is not a mental illness, but people on the spectrum are especially prone to mental health problems, as a result of social isolation, difficulties in communicating, bullying and discrimination. They are also more likely to be prescribed anti-anxiety, anti-depressant and antipsychotic medication long-term and to face issues of drug dependence and withdrawal.

The ordinary mental health services, based on recovery principles and short term interventions, do not suit autistic people, who require continuity and ongoing support. The One-Stop-Shops for autism are non-drug resources that support mental health, relieving pressure on both GP and psychiatric services. I do not want the situation where hundreds of people on the autistic spectrum are stranded, isolated and dependent on medication because there is simply nothing else<sup>5</sup>.

This petition calls for effective support of individuals affected and harmed by prescribed drug dependence and withdrawal, which includes individuals on the autistic spectrum. At the time of writing, the Highland One-Stop-Shop is still open and providing that support. I strongly urge the committee members to call on the Scottish Government to ensure the survival of the Highland One-Stop-Shop. This is a positive action that can be taken right now.

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<sup>2</sup> “Patients hit by shortage of drugs as prices soar”, The Times, 7 December 2017

<sup>3</sup> <http://www.bbc.co.uk/programmes/b09m4z7x>

<sup>4</sup> “Cash crisis could close the Highland’s only adult autism support service”, The Press and Journal, 1 February 2018

<sup>5</sup> “Suicide warning over autism centre closure”, The Inverness Courier, 11 October 2017