**A psychiatric patient’s journey, as told to Peter C Gøtzsche in an email**

I am a lay person who is reading a serialized version of your book “Mental health survival kit and withdrawal from psychiatric drugs.” It is both very interesting and disturbing. From some of your examples I ask myself: How could anyone function on two or three neuroleptics at once? And how could someone who has first-hand experience with neuroleptics and calls them dangerous be considered delusional?

I am a psychiatric survivor of sorts. At age 45 in the summer of 2018, I had an acute manic episode with psychotic features. This landed me in the hospital. At the same time, I was experiencing a medical problem in which I was retaining urine and could not void my bladder. I was in the hospital for about a week with a catheter. I was delusional the whole week. Nobody explained to me that I was having a manic episode. I was very talkative, and I thought they were making a movie about me. During the week I don’t think I slept at all. I’m sure that made matters worse.

Next, I was next transferred to a psychiatric ward with little explanation of what was going on. I was very disoriented and not very cooperative. They gave me a shot of Ativan (lorazepam) that knocked me out and gave me my first sleep in over a week. In the following days, I was told I was having a manic episode. I was interrogated by a psychiatrist and his students. I was constantly asked how euphoric I was and was asked to put a number on that from 1 to 10. I was not told anything about the drugs they put me on. It turns out they put me on 15 mg of Zyprexa (olanzapine), 15 mg of Restoril (temazepam), and a drug for peeing called Flomax (tamsulosin). I was in the psychiatric ward for a week.

I was told almost nothing about the medication, and I was not told much about mania or bipolar 1. The early side effects were constipation and slight agitation. I had never had serious mental health problems before the episode. I had a little bit of depression in college and some anxiety early in my working career. In the build up to the episode, I noticed I had more energy than normal and I had really enjoyed working on and solving a computer program that had stumped me for years but then I was making rapid progress with it. The sense of accomplishment turned into euphoria, and I continued working away on my project missing sleep for the first time in years and finally missing a whole night of sleep and feeling delirious the next day. My behaviour became more and more unreasonable as the day wore on until my mom deemed me to be unsafe and had me driven to the hospital by the police.

I was referred to a psychiatrist by my therapist who I had talked to mostly about philosophy and religion and a little bit about traumas and the hardships of life. The psychiatrist insisted on maintaining the doses and medications I was on in the psychiatric ward. He told me I should expect to be on the medications for life and that he was surprised the medication hadn’t caused me to gain weight. I trusted everybody I had dealt with, and I did not do any research on bipolar or the medications.

Prior to this I had worked for 22 years as an accountant. I had successfully dealt with many deadlines and even found time to go back to school part time to get degrees in computer science and applied math. I didn’t think my mind was deteriorating at all with some neurodegenerative disease that they now said I had. I was able to meet my fall deadlines reasonably well. With the medications, I noticed my agitation gradually increasing, my enjoyment of reading going from an enjoyable flow producing activity to something that made me anxious, and lastly my emotions flattening out. I was so busy with work that I didn’t really take proper stock of these disturbing developments. After I had met my work deadlines, things quickly became much worse for me.

About two months after the psychiatric ward visit, the agitation turned into uncontrollable pacing. I could not sit still. At night, I could not sleep. I had to pace around my home and then go back to bed and try to get comfortable, but I could not. I was seeing the psychiatrist once a month, but things were changing so quickly that once a month was not enough to properly monitor the situation. The pacing turned into panic attacks. The psychiatrist was slow to recognize this as akathisia. I emailed with him, and his responses were slow.

Finally, he told me I would have to consider going on Klonopin (clonazepam). I just wanted relief from the situation in which I thought I was dying. I did not research the pros and cons of this new medication. It brought almost instant relief. But it didn’t last. I was pacing again within a month and the psychiatrist was surprised I had built up tolerance so fast. Instead of talking about lowering the Zyprexa dose he increased it to 20 mg. I only took the 20 mg for one day as the symptoms got worse and I was on the verge of another panic attack. After going back down to 15 mg things settled down a little bit. By now it was December, and the emotional blunting was so bad that I could not close my mouth and I could not smile easily and felt nothing doing so.

At work, I struggled to solve routine problems. My brain was so slowed down and whenever I encountered difficulties, I went into a near panic state because I had never been so helpless before. I remember telling the psychiatrist at this point that I was depressed and had lost all my curiosity with life. He told me there might be some additional medications he could put me on, but it would be tricky because he didn’t want to flip me up to mania.

By January, I was already entering another work busy season. Somehow, I made it through April but was working far less hours. I was exhausted and did not get much enjoyment from working. My clients frequently told me I did not look well. I now know the doses of Zyprexa I was taking were the same as Eli Lilly recommends schizophrenic patients take. In the U.S., only 10 to 15 percent of schizophrenics work and many of them are only working part time. My point was that I was being sedated at a similar level as a patient with persistent psychosis when at best my illness is supposed to be episodic and the mania - if it happens at all - does not necessarily have to have psychotic features. Having me on an atypical antipsychotic seemed like massive overkill.

I did not know anything about drug withdrawals or tapering. All I knew was that I had low motivation, low energy, was emotionally stunted, sexually dysfunctional, and cognitively slow. This sad state of affairs had happened within 8 months of starting the drugs. I was told nothing about these problems upfront and they seemed to happen over time in such a way that I was trapped and locked into a bad situation.

I now know people frequently gain massive weight and develop type 2 diabetes in the first year of taking Zyprexa. I also now know about the brain shrinkage, cortex thinning, and brain atrophy that happens in the first year of taking Zyprexa. I asked the psychiatrist at the beginning if this would affect me cognitively and he said no. He either lied to me or is wilfully ignorant of the situation. So, I’ll cut this part of the story short and just tell you that I managed to convince my therapist and psychiatrist to cut my Zyprexa to 10 mg after 1 year. I know this is a deep cut but probably still pretty high up in the hyperbolic receptor binding curve.

I didn’t experience much of a withdrawal from this but neither did I experience much relief or improvement in my situation. By January 2020, he cut me down to 5 mg. Another deep cut. Still not much relief. In February, he cut me down to 2.5 mg even though he thought that such a small amount of a pill was not really necessary! By now, my sleeping was really starting to be affected. In the previous year, I had cut my Klonopin from 1 mg to 0.5 mg. It didn’t kill me, but it did increase my anxiety a bit. By February 2020, I was down to 0.25 mg Klonopin. I knew nothing about benzodiazepines at this point and the necessity of slow tapering. In late February, I went cold turkey off both drugs.

Big mistake. I had insomnia for a week. I couldn’t handle it and had to reinstate my dosages. I felt much worse after this. My psychiatrist didn’t tell me to go cold turkey at this point, but he did tell me I could go off one drug first and then wait a week and then quit the other drug. His advice was not much better than what I did do.

As the year progressed, my work got much worse. I could not tolerate being at work for more than a few hours. My revenue dropped by 50%. I became more and more depressed. My lack of motivation somehow got worse. COVID-19 was in full swing. By the fall of 2020, I was taking supplements and trying to taper by cutting the small doses I was on with a pill splitter. Somehow, by the end of January I was off the drugs, but I was not sleeping at all. I completely missed my January work deadline. I lived with friends for several weeks. And now, since February I have been living with my mother. I had to sell my home at a cheap price to pay off debts. I refuse to declare bankruptcy. I applied for disability but was denied.

My insomnia has improved a bit. As far as I know, I don’t have tardive dyskinesia. I have a social worker/therapist who tells me that my obsession with how God-awful neuroleptics and benzodiazepines are is perhaps confirmation bias. I have had two psychiatrists tell me they don’t think I’m bipolar because it’s been three years and I’ve not had hypomania, mania, or psychosis despite the insomnia and being off my meds. I finally broke down and had my general practitioner prescribe Wellbutrin (bupropion) for my anhedonia. I know you would think that’s a bad idea. However, I have felt a little better since taking it for four weeks. That might just be a placebo effect. I will not up the dose of that for fear of seizures and having that much further to go if I ween off it. I’m grateful neuroleptics didn’t kill me that first year, but I know they’ve damaged me badly. I was on them at high doses for a year and a half or so. And then low doses for another year.

I will conclude by saying I’ve taken great comfort in your works and the works of David Healy, Joanna Moncrieff, Peter Breggin, and Robert Whitaker. None of the psychiatrists I’ve talked to will validate my feelings and perceived experiences. They maintain that I have a late onset illness that requires medication for life. But if Joanna Moncrieff maintains that lithium is so toxic, no one should take it, not even people with bipolar, so what’s left? The anticonvulsants have not been shown to be much better at controlling mania, and antipsychotics completely destroy quality of life. What am I to do?