

## **PE1651/NNNNNNN**

Darius Ghanat submission of 14 February 2018

I didn't get into the mental health system the way that most psychiatric survivors do. However, once I was in, I ended up injured and disabled because of it. I have Tourette Syndrome (TS), a neurological disorder that causes involuntary movements and sounds called "tics." In 2010, at the age of 17, when my tics unexpectedly became debilitating, my family started taking me to one specialist after another. The neurologist who treated me was considered the top in her field and a prestigious movement disorder researcher, so after months of waiting and suffering, we thought I was finally going to get the help I needed. At my first appointment, the neurologist prescribed Abilify (aripiprazole) off-label to help manage my tics. My family and I were new to the "medication world" and so of course, we trusted her knowledge. It was never explained to us that Abilify (aripiprazole) was an antipsychotic, nor would we have expected one to be prescribed to treat tics. It was also never explained to us about any of the dangerous side effects or withdrawal complications in this class of drugs.

Needless to say, this drug therapy went terribly wrong. I quickly began to experience horrific side effects that became so severe I was not able to leave my house. By the second week of taking Abilify (aripiprazole) I had all the typical side effects of an antipsychotic and then some. I was shocked by how quickly it completely deteriorated my health. I was walking around in a drug haze and I felt so numb and lifeless. I started to experience extreme restlessness, not realizing at the time I was already in the early stages of akathisia. I lost my ability to experience any pleasure from the activities I normally enjoyed. I now realize that I was also in the early stages of tardive dyskinesia, as I had developed tremors and hyperkinetic movements. Even after reporting these movements to the doctor, she did not pick up on the fact that I was developing tardive dyskinesia and downplayed my symptoms. The doctor's treatment literally made me so ill that I was unable to come to her for my appointments anymore, so she agreed to treat me via email. The doctor regularly told me to tough out debilitating side effects and when we told her that it was too much to bear, her only solution was to add more medication, which included the SSRI Zoloft (sertraline). Once adding the SSRI, it was still nowhere near enough to counter the side effects of the antipsychotic, and it further complicated my situation by adding on even more agonizing side effects of its own. Every afternoon my anxiety was so intense that my teeth were constantly chattering and all I could do was sit on the floor and shiver convulsively. The doctor then suggested that I raise the dose of the SSRI even higher, but my parents and I thought this was a terrible idea since along with all the other side effects, I was experiencing excruciating headaches that felt as if my head was going to crack open. After over a year of living this way, my parents and I decided that I should get off all medication. We discussed this with the doctor, and since I was homebound because of the medication and my quality of life was actually worse, she agreed. The only guidance the doctor gave us

about the “withdrawal process” was that we needed to “do it slowly,” and that “it might be a little bumpy.”

To be honest, nothing could have prepared my parents and me for the hell we were forced to live in for the next six months. The first month of withdrawal, I was basically in a comatose state. I would sit on the floor in the same position, unresponsive to anything for hours. My mind had become a black void, completely empty of thoughts, and I lost my ability to think. It was as if my life had stopped and I was living in a constant “nothingness.” During the times that my thoughts did return, I was suicidally depressed. All I could do was sit on the floor and constantly think about what a worthless person the drugs forced me to think I was. I developed extremely distorted body image issues and self-disgust, where simply looking in the mirror would set off my symptoms.

As time went on and I had less and less drugs in my system, the suicidal ideation increased. My mom recognized that I was going through the DT’s (delirium tremens). I would sit on the floor in agony because I thought I had thousands of bugs crawling all over my body and burrowing into my skin. I would scratch my skin until it was irritated and sometimes bloody in an attempt to stop the sensations. Eventually, I also became homicidal and extremely violent. For our safety, my parents had to remove all sharp objects from our home, which included all forks, knives, and scissors. I needed to be monitored 24/7.

Because of the lack of resources, my parents were forced to close down their business so that they could be with me. I had such severe personality changes that I became completely unrecognizable to my parents. At that point, when my mom looked into my eyes she saw a complete stranger. I would suddenly go from total calmness into maniacal rages where I would scream at the top of my lungs for hours. During these rages I would throw things and hurt myself, which included ripping my hair out and forcibly banging my head on walls and windows.

I had become so paranoid, I was afraid to leave the house. I thought that if anyone saw me they would kill me because the drug made me think I was so ugly. My parents were constantly on edge because they never knew exactly what would set me off. When my parents reached out to the medical community for help, they were told to put me in a mental hospital, where I would not only be further medicated, but they would not be allowed to see me. This made absolutely no sense to my parents because I was trying to get off the medication, and it was the very reason why I was this way to begin with. So they decided we would “tough it out” as a family and hoped that it would pass quickly.

Sadly, that wasn’t in our favor as my withdrawal duration lasted over six months. At the peak of the withdrawals, one of my worst rage episodes took place on Christmas Eve. It lasted for well over 36 hours and I was near death from complete dehydration and exhaustion. My body was in constant motion during this period and I was not

able to sleep, eat, or even have a sip of water. As my caregivers, my parents were also put into the same dire situation. I was screaming in anguish, despair and hopelessness with an incredibly strong urge to kill myself and others. I was totally overcome with a feeling that words cannot describe. I felt as if I was experiencing torment so insane I didn't know what to do with myself and that there was nowhere to escape the madness. I was hysterical, paranoid, and delusional.

Once my family and I got through the horror of withdrawals, my parents really thought I was through the worst of it all and would start getting better. As time went on, we came to realize that the medications had permanently damaged my mind and body. Going into the treatment, the doctor had put us under the impression that there were really no side effects to be concerned about at all. She told us everything we wanted to hear by portraying the drugs as some type of miracle, giving us a false hope that I would get my life back. Since withdrawal, I now live with so many new illnesses that I never had before taking medication. Some of these include: breathing problems, akathisia, tardive dyskinesia, OCD, psychosis, sleep and speech disorders, and acid reflux. Also, my original Tourette Syndrome has progressed to become so bizarre and complex.

Even after I was off the medication, the doctor assured us that all the side effects would eventually go away after two years. Now years later, I still spend my days isolated and pacing, unable to sit on furniture or sleep in a bed. I eat standing up and sleep on the floor without the luxury of a pillow or a blanket. My drug-induced symptoms force me to live this way.

Whenever we try to seek new help for me, doctors throw their hands up and say there is nothing they can do and they refer me on. I have tried a wide variety of treatments, including alternative and natural medicine. It's hard to counter the damage of medication once it's been done. So many doctors will not even take me on as a new patient because they already know from my initial information provided that they will be unable to help me. Often when I try to explain my new symptoms to the doctors, I completely lose them in the process. I had my whole life ahead of me, but now I have become disabled and homebound. As it stands now, I live with my parents under their complete care. I may never be able to live on my own, to work or have a career, or the chance to have a relationship. It has been over five years since I have taken my last pill, and I am still experiencing disabling side effects from the medications. My story further emphasizes the dangers and futility of psychiatric medication and withdrawals. As in my case, it was used to treat a physical illness instead of the typical mental health uses. In an attempt to try to "fix" my brain, they ended up destroying it. Doctors are simply not knowledgeable enough about how these drugs effect the brain and are definitely not appropriately trained in how to help patients to properly taper to prevent horrific withdrawals.