

PE1651/KKKKKKKK

Samantha Long submission of 18 May 2018

My gp did not warn me about the side effects of metoclopramide. They did not recognise the side effects of metoclopramide nor did they offer appropriate treatment options. Drugs harmed me, and I have had a substantial amount of time off work. I had two jobs one of which I have now lost as I am no longer capable of doing it due to my neurological condition.

I am due to return to the other employment soon with reasonable adjustments that have been put in place so that I can work with a level of disability that was not present before I took metoclopramide. I believe it could have been much worse. I did not know at the time that metoclopramide has an action similar to many anti-psychotics and therefore similar side effects including neurological disorders. I was also unaware that its use had been restricted due to the neurological disorders that had been previously reported.

I developed Akathisia after taking a single dose of metoclopramide on the 5th of December 2017. I still have symptoms many months later. I had been taking metoclopramide for 7 months as and when needed for gastric emptying and took 44 tablets in total and after my adverse reaction in December discontinued their use. Prior to December I was working full-time and completing my Masters degree in counselling and I was in the final year.

I encountered barriers to my recovery which were:

Problems describing how bad Akathisia is to get the support and understanding I needed.

I feel it is primarily a sensory experience that gives rise to emotional distress and agitation. Descriptive language develops out of shared experience. Due of a lack of shared experience, there is problems describing it. We tend to fall back on emotional descriptions which inadequate. I have put together a description as my experience has been that my symptoms have been dismissed as a mental health condition, though my symptoms have been unlike anything that I have experienced before.

Doctors can only see the emotional response to the sensory experience of Akathisia. Their frame of reference is the medical model. This can end up with being diagnosed with a mental health issue. My mental health was questioned, and it was only because I took in journal articles with different treatment options to my gp, that I was able to get the help I needed.

Akathisia lasts longer than the half-life of the drug you ingested. Total elimination of metoclopramide is 72 hours. My GP could not understand that extrapyramidal symptoms can continue a lot longer, so looked at alternative explanations i.e. mental health, because my experience did not fit with her understanding or training. My GP thought that it was unlikely that my symptoms were down to a single dose of metoclopramide. I found a useful article that shows that a patient showed a year of disability due to Akathisia, after only taking the drug for two days.

I believe the lack of evidence, misunderstanding and misinterpretation has led to these side effects being vastly under-reported, especially when they are linked to medication for mental health problems when they can be easily misinterpreted. Akathisia is not a mental health problem, it is sensory torture and I have not found anything to alleviate its symptoms.

I believe Akathisia is also related to attention. Selective attention helps tune out unwanted stimulation and this does not work with Akathisia, there is no off button, it is on/on full volume and the feelings of helplessness and despair come from this I feel. Usually your brain tunes out unwanted stimulation through a process called accommodation. You can experience this if you listen to a pure tone of say 2000 htz, it will appear to vary in pitch and volume when actually it does not change. Accommodation is switched off in Akathisia, it screams at you with no respite.

This is what my experience of Akathisia was like:

There were parts of my brain that felt like they were filled with concrete. The rest of the front of my brain was frantic trying to get through the concrete but just not happening and this was the source of my agitation. I read that dopamine helps different parts of the brain communicate with each other, it felt like this was switched off.

I had a rod of absolute terror in my chest which somehow seemed to connect my stomach and brain in some kind of escalating feedback loop of dire distress, feeling like I was locked in my own body, like being buried alive underground. There was absolutely no escape.

I had sensations in my arms and legs that was like the feeling you get when someone scratches a fork on a plate, but it was stuck at the top of the screech and nothing I did impacted this feeling, which in turn made me feel incredibly helpless. I had a feeling in my ligaments like they were a mass of rubber bands and only relieved by moving. I was agitated when this was coming from ligaments that I couldn't move, especially deep within my shoulders.

Initially movement did not help, it was only when I was less agitated around a week and a half later that I was moving around a lot.

I believe that Akathisia has a personality, it felt like my brain had been hijacked and thoughts and feelings were not my own. These were:

A certainty I was going to die

A feeling that I had damaged my nervous system beyond repair and so I needed to kill myself because I would never have a quality of life again - I felt this within 4 hours of taking metoclopramide.

A total lack of empathy for other people, I did not care about anyone else

I did not care about the consequences of my actions – they were tiny compared to the degree of my suffering (luckily my head overruled my feelings on this one)

Uncharacteristic aggression

Intolerance/irritability of judgement (though this may be a magnified part of my

personality).

I had dissociative amnesia, I forgot what I was (human) who I was and my name, who my partner was.

Time drags. Things that happened yesterday seem like last week. Usually it is the opposite for me.

I can't learn, my short-term memory isn't reliable. But I can do things from long term memory that are a skill. Thinking hurts and can set off another bout of Akathisia.

Bright lights and noise at times I can't stand and have to be in a dark room.

Sometimes I can't hold a conversation because Akathisia is constantly tapping my shoulder, demanding my attention.

I have been obsessed with talking about Akathisia and being locked in. I've never had obsessional thoughts before.

Paranoia

Neck stiffness

Loss of sense of smell (1 month)

Muscle spasms/twitching

I'm usually very laid back and people often commented on my calm nature. When I get windows none of these thoughts and feelings are there.

This was my experience during the first 8 weeks of the reaction, after this time my akathisia grew less and other symptoms such as problems with walking and cognitive problems were prominent. I had to make lifestyle changes as I was having severe muscle spasms in response to working and at the end of January I had decided to postpone my degree. My condition continued to escalate and in the middle of March I woke up and my speech and walking had deteriorated, and my akathisia had returned. I had an emergency GP appointment who sent me straight to hospital. The hospital; conducted some tests to try and determine a cause and I was told that they could not find a cause and initially diagnosed me with tardive dyskinesia. A week later I went to A&E and was admitted due to swallowing difficulty. I was admitted for five days and all of my tests came back negative including an MRI and the neurologist that I saw said that the symptoms were unrelated to the drug reaction and that my symptoms were psychological caused by anxiety. I have been unable to work, and my symptoms have improved with rest but are still present. I note that there are lots of neurological conditions that do not show up on medical tests including traumatic brain injury and ALS. I asked about the basis of the diagnosis that I was given and was told that my symptoms 'did not fit the pattern associated with a reaction to metoclopramide'. However, all of my symptoms are listed as side effects on the patient information leaflet detailed on the MHRA website, journals and have been reported previously as side effects of this medication. Long-term effects of this medication are not recognised. The NHS have acknowledged that the side effects were caused by the drug and that it was mis prescribed without my informed consent. However, they have said that the symptoms that developed 3.5 months after my initial reaction are unrelated.