

PE1651/HHH

Sammy Long submission of 12 January 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 had to have time off work, it could have been much worse.

See my account below on what happened to me:

I developed Akathisia after taking a single 20mg dose of metoclopramide on the 5th of December 2017. I still have some symptoms 1 month later.

I was prescribed Metoclopramide to help food move through my stomach faster. Before I took Metoclopramide I was mentally very well, in fact in the third year of a Masters Degree in counselling and had addressed all sorts of issues as part of my training - not perfect but good enough.

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 are at best woefully inadequate. I am have put together a description that cannot be so easily dismissed as mental health. I've had mental health issues and my experience was far worse.

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 months of disability due to Akathisia, after only taking the drug for two days.

I believe the lack of evidence, misunderstanding and misinterpretation has lead 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 that does not abate.

I believe that it 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. Looking at a diagram of the brain these were the cingulate gyrus on both sides and the left side of the cerebellum at the back.

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.

Looking at other accounts there is remarkable similarity in statements used by other people that I identified with. 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).

When I get windows none of these thoughts and feelings are there.

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, I'm usually very laid back and people often commented on my calm nature.

I hope I have done justice to my description of Akathisia to help people get some understand and support for this debilitating condition.