

## **PE1651/CCCCC**

Marita Franzén submission of 31 January 2018

Following my youngest daughter's birth in 2002, I never seemed to get physically back on track. I was plagued by aches and pains, particularly along my spine. A few months postpartum I was diagnosed with hypothyroidism, and treated accordingly, yet the pain level remained the same.

Up until then I had avoided pills at all costs. I didn't even touch paracetamol. Still, due to aforesaid pain I had, by the time I went to see the doctor about my physical issues, got myself into a codeine habit. This I did via local pharmacies and OTC Co-Codamol. A while later, in 2005, I landed at the local pain clinic. My GP had prior to this told me that I needed to "change my life situation", probably referring to both my relationship and my stressful work as a secondary school teacher. However, I was fashionably stuck: at the time I had two young children and was a foreigner living in the UK. My social network was slim, and I felt I had neither emotional nor financial security.

By 2006 I was on sickness benefit, and probably more down, mentally speaking, than I realised myself. (I have not worked since.) At the pain clinic I was given a prescription for Amitriptyline - but not due to being down. No, in fact I was reassured by my doctor that I didn't need anti-depressants for my mind's sake. The Amitriptyline, he said, was supposed to ease my physical issues: improve my sleep, most likely reduce my pain experience, as well as ease many other symptoms. I was told that I had a "Fibromyalgia type condition", but this diagnosis has now left my notes. With regards to the Amitriptyline I felt no effect whatsoever, and with hindsight I realise that gradually not taking this medication regularly, and later on quitting it cold turkey, probably put me in an even worse place than before. Yet, I knew nothing about withdrawal symptoms at this stage. Neither was I aware of the importance of taking it regularly.

I was now heading for disaster: My pain level went up; sleeping deteriorated. Alongside pain I suffered vertigo, disabling IBS and bladder problems. Moreover, due to endometriosis I ended up needing a full hysterectomy and oophorectomy, sending me straight into menopause at 34 years of age. A neck issue were later to become major enough to require surgery – not to forget the Trigeminal Neuralgia that occurred, a condition that, that alone, could well have made me suicidal. However, although I often stated that I was sick of life with pain, the pain doctor assured me that "oh no, YOU are not depressed" – and then went on to prescribe a then new "miracle drug" called Cymbalta (duloxetine). This, he said, would help ease the pain! I look back and I find it beyond ironic that I was not depressed before I started taking anti-depressants – but taking them gradually led me into depression and suicidal thoughts.

As for the Cymbalta: back in 2007 when first taking the drug, I initially felt that health did improve a bit. At least in terms of pain management. This feeling didn't last long however, and the dose was swiftly increased – to no avail, I hasten to add. No one in the medical profession ever thought of evaluating my use of this substance, and by 2012, after some 5 years on Cymbalta, I was suddenly polypharmacy. There were Gabapentin, Oxycontin and Oxycodone – not to mention all the pills needed to treat my stomach problems. A long line of pills had little by little been added to my list of medications. Somehow I also had to combat the side-effects – and that was done with even more pills. Thus my stomach was in turmoil. My short-term memory had gone completely - and I was, to be blunt, a living shell. My intellectual ability was also seriously affected, so much so I struggled to read the simplest magazine. Today I have very few recollections of my life back then, apart from some particularly traumatic incidents, and a few major family events. I tend to remember via photographs, and I see a woman who went from being an academic, a teacher, a woman who enjoyed conversing and socialising – to being a human void.

Now, the disaster didn't end there. It had, in fact, only started. By 2013 I was in a terrible state: Dependent on various drugs and with very little respect left for life itself. And, for the record, I had now been seeing a clinical psychologist for quite some time. I was both truly depressed and a physical wreck heading for death, mixing drink and drugs in order to numb the general pain. Body and mind went down skid row, hand in hand. By the grace of God I found my way back home to my native country towards the end of that year, and I was welcomed by family who were appalled to witness the state I was in. My children's safety and emotional stability had, by the same grace, become my only focus – and I realised that I needed to get myself healthier, mainly for their sake to begin with.

So, having managed to quit the opioids just before leaving the UK, I now decided to rid myself of the other pills. Why so? Because I had realised that no matter how many pills I consumed, I was still in pain. Furthermore, there was that tiny bit of awareness left in me, that made me realise that I had turned – *thick*, for want of a better word. And that made me angry in a way that supplied enough energy to at least try to detox. Despite having difficulties understanding the written word, I had started doing some research into the medications I was still on. And I swiftly understood that not only did the pills make me sick, suicidal, forgetful and mentally impaired – they could also be hard to come off. Determination was high though, and after having stopped taking Gabapentin without much trouble, I initially listened to my then GP's advice on how to wean off Cymbalta – a decision which nearly cost me my life. I hasten to add that my GP didn't know better, so there's no blaming on that account. But there is this: psychiatrists, general practitioners, specialists – medical staff at large – MUST update themselves via new, much needed guidelines. These yet to be seen guidelines could make the difference between life and death, and that is something I can testify:

Following the doctor's order on how to discontinue the use of Cymbalta, I ended up

having painful, debilitating stomach issues that made me pass out. I also suffered spells/fits during which I lost consciousness for up to 30 minutes, and these incidents led to – yes – potentially fatal falls. During one such incident I lost consciousness walking down a flight of stairs, and it's a miracle that I didn't break my neck; on another occasion I passed out in the bathroom, ending up with broken teeth and a generally sore body. I also turned suicidal and completely unable to sleep, which in turn very nearly led to psychosis. During 2014/2015 I was thus a frequent visitor at A&E, and also hospitalised several times, due to aforesaid symptoms - as well as suspected epilepsy. Psychiatric diagnoses were also added to my notes. I was bipolar, borderline and manic... Needless to say, I don't have epilepsy, and the psychiatric diagnoses have since vanished.

The first attempt at quitting was interrupted due to, mainly, my depressed mood – and my GP told me that my worsening health was a sign of me needing the medication. Though, the more I learned about the “chemical imbalance myth” and the so called “discontinuation syndrome”, the more determined I grew to stop taking the drug. After another failed attempt, again in accordance with the doctor's guidelines, I came across a US online help group and learned about the method of decreasing the dose by only a little at a time, 10% or less.

It ended up taking me over 3 years to successfully quit taking Cymbalta. My mental health is, today, better than ever, however I am still a physical wreck, and one doctor I'm currently seeing recently told me that she thinks my body is affected "down to cell level". I can't but wonder what the consequences are/will be of having used this drug for 10 years. Of course polypharmacy plays its part in my body, however I know when disaster struck, and I am absolutely certain that psychotropic drugs, and mainly Cymbalta, were the kind of medication that sent my whole being into turmoil. I also know, without doubt, that I could not successfully have discontinued the use, had I not encountered the above mentioned self-help group (followed by other similar groups). Support from fellow fighters, as well as learning a safe method to decrease the dose, are essential tools. So: We need a safer system, both with regards to prescribing psychotropic drugs – and with regards to assistance when the patient is due to discontinue the use of the drug(s) in question.