

PE1651/DDDDDDD

Margaret Skinner submission of 15 February 2018

I wish to submit the following in response to the above petition.

I have recently had 3 years of my life cruelly whipped away from me due to irresponsible prescribing of mind altering drugs.

In 2014, having realised I had become dependent on over the counter tablets containing codeine (taken originally for period pains), I asked to be referred to my local Substance Misuse service because I wanted support with a taper which I had managed successfully myself but was struggling with the last part of.

I was told my only option was to be put on the drug Subutex, a very strong opiate containing buprenorphine. As this was far stronger than what I was already taking I could not see the logic in this at all but was told a taper could not be supported because the safety of the tablets I was taking could not be guaranteed. This was madness. These tablets were on sale at every reputable pharmacist and the amount of codeine in them was minimal. When I questioned this my CPN agreed with me citing the fact the service was really set up to deal with people addicted to hard drugs like heroine or cocaine.

This is also madness. There are thousands of people dependent on over the counter medication, desperately struggling to get off it, who have innocently taken these tablets for period pains, headaches, migraines, joint pain & so on, not realising that codeine is addictive. Or they have been prescribed codeine in some form or another for pain and taken it in good faith, believing if a doctor is offering it, it must be safe.

For two months I researched the drug Subutex further and was horrified to discover many many people having been plunged into a horrific withdrawal lasting months and sometimes years when trying to come off it but when I voiced my fears, I was assured that I would only be on a very small dose and would be weaned off after a month.

I felt stuck between a rock and a hard place.

Reluctantly I agreed to give it a try and on the Monday, the 9th February, 2015, I was given my first dose. I was shocked when I saw how much of it I was prescribed because I knew approximately how much I should be given in relation to the amount of codeine I was taking. In my opinion it was far too much. This was borne out when about an hour later, I began to be dreadfully sick. I continued to vomit right through to the next day when it finally stopped. Contacting the Substance Misuse Clinic I was advised to take the next dose which I did and once again, I vomited for hours.

It was not until Thursday that my dose was finally changed and interestingly, it was cut by more than half, bearing out my conviction that the original dose had been far too high. To this day I have not seen the doctor who made this prescription - all communication was done through a keyworker.

Once the dose was changed I stabilised which I was relieved about as I started a new job the following week! After the month had passed, I began the taper which I was assured would only take another 4 weeks. The dose was cut by 50% and after a fortnight I began to feel very unwell. Thinking I had picked up a bug, I struggled on but never seemed to get better. I appeared to be picking up urine infections one after another and I felt sick all the time and dreadfully cold.

One Friday morning I woke up and literally couldn't get out of bed and had to crawl through to the bathroom. At lunchtime I took my dose of Subutex and in the afternoon the symptoms miraculously vanished. The next day I was able to get up but was plunged into a state of absolute terror as the worst suicidal thoughts I have ever experienced raced through my mind for hours on end. Again at lunchtime I took my dose of Subutex and was fine in the afternoon. It was only on the third day when the same thing happened that I suddenly realised this was all connected to the Subutex taper which had obviously had been too much too quick.

As my daughter was due to give birth to her second child at any minute, and I was the designated birthing partner, I very quickly reinstated the original dose of Subutex in order to get through that and support her afterwards. Contrary to what I expected to happen, I did not get better and continued to struggle with an extreme fatigue, complete loss of appetite, frequency of micturition, diarrhoea, lack of sleep and an ever-increasing anxiety. All these symptoms continued and worsened in the following weeks until I was eventually signed off work. The diagnosis was depression and anxiety but I knew I was not depressed and the anxiety was of a scale never before experienced which left me shaking, heart racing and pounding and totally unable to sleep.

My GP suspected ME and prescribed Diazepam for the anxiety and Propanalol for the racing heart. She also tried to get me to agree to go on Mirtazapine, an antidepressant used to treat anxiety, loss of appetite and sleep. I was very reluctant because I had, in the past, tried 5 different antidepressants with no success whatsoever and had decided not to go on any others but look for different solutions not involving medication. I also did not want to take the Diazepam for fear of addiction but after 3 days and nights of acute anxiety and no sleep whatsoever, I finally succumbed. It did not help sleep at all so a fortnight later, I agreed to give Mirtazapine a try.

After my first tablet, I slept the whole night for the first time in weeks and most of the next day! There did not seem to be any noticeable difference to my mood but my appetite and sleep gradually improved so I was grateful for that.

The anxiety continued with varying intensity but I was delighted to discover I could take Diazepam when it became unbearable without any dependency apparently forming and I continued in that vein as I tried to recover. I made an attempt to get back to work via a phased return but collapsed twice and couldn't even manage staggered mornings. The dreadful fatigue persisted and by July, I realised I was never going to get back to my job so resigned. It was a relief at the time to have that stress taken away.

In 2016 I tentatively started counselling training with a local agency consisting of 10 full weekends between January and June. Although hard, I was able to complete this and began counselling clients in August of that year. Some of the girls on the training were going on to pursue a Diploma in Person-Centred Counselling at the local University and I decided to try for this myself. I was delighted to be accepted and started the course in September.

The fatigue continued to be a problem so I returned to the doctor and asked to be referred to a specialist. As a result of this, I was formally diagnosed with Chronic Fatigue Syndrome in October (2016). I found it a struggle to keep up with coursework and assignments on the course but felt I was managing. However I was coming down with every bug imaginable and by Christmas, was completely exhausted. The anxiety had increased as well and I was glad that I still had plenty of Diazepam from the original prescription (my GP had repeatedly prescribed them without me asking for any) - I continued to take them intermittently as and when needed.

On returning to University in January after the break, I found I was beginning to struggle again and succumbed to yet another bug. One of my cats became seriously ill around this time and my stress levels soared as a result. I seemed unable to cope with anything 'extra' on top of the weekly commitments and the simplest of tasks seemed like incredibly hard work. One Thursday in the last week of January, I became increasingly ill and eventually collapsed in the counselling agency where I was working voluntarily.

I appeared to have regressed a year as all the same symptoms reared their ugly heads once again and I was at a loss to explain this. As the months went on, I became increasingly more and more ill especially when I tried to go out anywhere. At first taking Diazepam seemed to be the answer and made situations manageable but as time went on, the same dose wasn't working any more and I refused to increase it further as I knew that was a slippery slope I didn't want to be on.

By July I was virtually housebound.

And then my sleep began to be affected.

I went from getting 8-10 hours sleep a night with a nap of about an hour around teatime to getting one hour's sleep at night and no ability to nap during the day at all. I would waken after an hour with an anxiety which was completely off the charts, heart racing and pounding, sweating, terrified, exhausted, feeling dreadful. Along with headaches, sore throat, high temperatures, tinnitus, joint and muscle pain, restless legs, no appetite whatsoever, frequent micturation, severe nausea and weakness such that I could hardly get down the stairs.

By 8 a.m. when I got up to feed my cats I was as weak as a kitten and could hardly make it through breakfast - I was desperate to get back into bed again and lie down. By August I was entirely bedbound and extremely perplexed as to what on earth was happening to me. My body appeared to be going into withdrawal every night. But what from? It didn't make sense. Family and friends rallied round to

support me but were as perplexed as I was. Home visits were arranged with GPs who diagnosed urine infections where none existed, indigestion or nothing at all. I called an ambulance out twice, unable to manage my alarming heartrate but nothing untoward was found. So many times I didn't think I could carry on and prayed to die continually.

I was unable to do anything for myself - wash, feed, read, do housework, concentrate on anything - and was therefore unable to research my symptoms until late September. By then I had noticed that I was going roughly 4 or 5 days between doses of Diazepam and, knowing of its half life, wondered if my 5 mgs dose was wearing off in that time and I was somehow going into withdrawal in between. I looked up Diazepam withdrawal and was amazed to see every one of my symptoms listed! But I was still perplexed. How could I withdraw from a drug I was still taking?

Further research resulted in finding interdose withdrawal and also the Benzobuddies forum and at last the confusion of the previous months was explained by others who had gone through and were still going through exactly the same nightmare. I began asking questions which were clearly and succinctly answered along with necessary support and encouragement and I finally realised what had happened and what I needed to do.

I decided to see if I could manage to go longer in between doses of Diazepam and my next 'break' was 8 days. I then decided nothing could be worse than the hell I was going through already so I stopped altogether on the 13th October. At that point I was in acute withdrawal and I stayed there for another month or so and then gradually symptoms began to decrease ever so slowly. Each day at lunchtime, I made myself get up and dressed and lie on top of a different bed in the house then gradually began trying to sit up in a chair for short periods of time. I also started to try taking a walk outside. At first I could only manage 5 minutes - then it was 10 - then 15 and eventually I managed to work my way up to 30 or 40 minutes fairly comfortably. By January of the New Year I was beginning to have one or two 'windows' (where symptoms improve considerably) in the month and had started to take the car out for short journeys.

I am now 4 months into withdrawal and all these improvements continue at a very slow pace but bad days are still very much in force. However the couple of 'windows' I get each month give me some hope that I will eventually emerge from this intact - but I am also in despair that I will have to go through it all again with Mirtazapine. By all accounts, coming off that drug will be just as hard.

I feel very bitter that this was not picked up by the medical profession at all and I was left to figure it out for myself. It has cost me my job, my income, my further education, my relationship with my daughter and sister, friendships, time spent with my young grandchildren and I will eventually have to rebuild my life as best I can when I am at the point of being able to do so.

I have been completely horrified by this experience and undeniably shocked to the core by what these drugs can do to someone's body and brain and how that breakdown can have a similar effect to a tornado through someone's life, wrecking

everything in its path. All along the way, I have struggled to be believed and have had the humiliation of having to class myself as mentally ill in order to get any support at all from social services. This is completely and utterly wrong.

There needs to be far more recognition of the damage these drugs can do and the length of time some people will experience withdrawal as well as the very distressing symptoms involved. Time and time again, people are being misdiagnosed because these symptoms are not being recognised for what they are or, even worse, people are being put BACK on the same drugs because Psychiatrists and GPs are unable to see that the drugs themselves are causing a problem.

Reinstatement of these drugs causes worse problems in the future and only means a more horrific withdrawal further down the line once realisation dawns.

Had recognition of what was happening to me been available when it was in the initial stages I could perhaps have been saved an immense amount of heartache, distress and absolute misery, not to mention 3 whole years of my life!!