

Dopamine agonists, hypersexuality and relationships

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Hypersexuality linked to use of dopamine agonists.....hmmm...where to start? Obviously, I have personal experience on this matter and am not ashamed or frightened to admit or share my experiences. If it helps others in knowing they are not alone or weird or losing the plot, then it's worth sharing.

Dopamine agonists are amazing drugs but extremely powerful too , more toxic than chemo and sold on the black market as a sex drug. Looking back I know I didn't see myself as acting any differently, but now the fog has lifted, due to dramatically reducing my dosage down to the minimum recommended therapeutic dose, I can see why those near and dear to me no longer knew who or what I was. Scary!



Before writing, I googled the subject. No surprise, the subject of S.E.X frequently played down ..."affects small amount of patients...." Ha! Not!!! Why are we still so Victorian in our attitude towards sex? Making it taboo is simply not addressing a problem which, for many I have spoken to, has cost them dearly. I used to joke in clinic to my consultant that I could become a prostitute but wouldn't make any money as I'd end up paying the customer.. I was joking but really shouting for help in a roundabout way. I wasn't heard. Ken took to sleeping on the sofa just so he could sleep.

I recognised things in general were just "not right" but I didn't know how to help myself. And I didn't relish giving my meds up as my control was so good I could hide the fact I had Parkinson's. That was massively important to me. My GP eventually referred me to a psychiatrist who discharged me after two appointments, so I was left to deal with something I knew was becoming out of hand myself. The reality is that I lived my private life out in the open for all to see and judge. And judge they did.

On the *move*

I recently watched "Sex, lies and Parkinson's" the Channel 4 documentary made in 2011. Oliver Cheetham followed me for 18 months and became not only a confidante and friend but truly understood what was happening to me and my family. He didn't have an easy task of taking 30 hours of footage and condensing it into a sharp and hard hitting 25 min programme. He did an amazing job and I'm proud to have been involved in it.

That woman is no longer me but it is a true portrayal of family life being kicked in the guts not only by a diagnosis hideous at any age but at 35 almost impossible to comprehend. Add to that a cocktail of brain altering chemicals akin to being high on crack cocaine and ecstasy and Bang! Recipe for disaster.

I'm well known for discussing dopamine agonist side effects, am not ashamed or embarrassed, and refuse to ignore not only my own plight but that of many others. I'm not saying ban these drugs, just treat them with respect and awareness of potential impulsive and obsessive behaviours. And involve family and friends. No one stopped me; for some I was their entertainment, happy to spend, spend, spend on everyone.

I eventually realised I needed control before I lost everything dear to me. I reduced my own dosage with both my GP and consultant's approval. Not all are so lucky - some may have access to specialists in this field but I'm aware these are far and few in between.

But we the patients are ultimately the most specialised specialists. Learning the hard way but sharing our experiences and making others aware is what we need to do. I was devastated at some of the backlash I got from fellow parkies for highlighting my experiences. I'm no longer affected the same way. So many people have confided in me, their stories often heartbreaking. Not only are we fighting to come to terms with a cruel diagnosis but battling the devils on our shoulders. So I encourage you, if you are at all affected, tell someone, get help, take back control. wish I could turn my clock back. But I can help others realise what is right and normal and what is very much a drug induced hell.

