

Parkinson's UK policy statement

Impulsive and compulsive behaviour as a side effect of Parkinson's medication

"My Parkinson's drugs turned me from an occasional bingo-goer, to somebody who amassed tens of thousands of pounds of debt through compulsive gambling"

Patricia - Person with Parkinson's

What we believe

We believe that no one affected by Parkinson's should have their lives ruined by impulsive and compulsive behaviour as a side effect of Parkinson's medication. Professionals and pharmaceutical companies have a responsibility to raise the awareness of these side effects and do all they can to mitigate the risks. The pharmaceutical companies should work towards developing medication with less harmful side effects.

What we think should happen

- Medical professionals should be aware of this side effect of Parkinson's medication and its potential to significantly damage the lives of people with Parkinson's and those around them.
- Medical professionals should take account of any underlying predisposition to impulsive and compulsive behaviour when making prescribing decisions about Parkinson's medication.
- Medical professionals should always discuss impulsive and compulsive behaviour with people affected by Parkinson's, including carers when prescribing Parkinson's medication.
- Professionals should actively monitor those taking medication for any signs that they may have developed impulsive and compulsive behaviour.
- People who experience impulsive and compulsive behaviour should have their treatment reviewed and changed as necessary after discussion with their consultant or Parkinson's nurse.
- Families and carers of people with Parkinson's should always be involved in discussions about impulsive and compulsive behaviour, both before prescription and in ongoing reviews.
- Pharmaceutical companies should ensure information and support on managing these side effects is easily accessible to professionals and people affected by Parkinson's.
- Gambling organisations should ensure restrictions are in place to protect vulnerable people from the impact of unlimited gambling.

Why we believe this

We know that impulsive and compulsive behaviour can have a devastating impact on people's lives.

They can affect people in many different ways, including binge eating, compulsive shopping, compulsive gambling or hypersexuality. The consequences can include family breakdown, loss of life savings and criminal prosecution.

“I was living a Jekyll and Hyde life, slipping almost daily into a time-consuming fantasy world of chat lines, dating sites and internet erotica and pornography. Matters came to a head when the police arrested me on suspicion of downloading illicit images. Since then my life has been a nightmare, with my family under pressure and split apart” – Man with Parkinson’s

People affected by Parkinson’s may not associate the changes in their behaviour with Parkinson’s medication. They may be too embarrassed to talk about this behaviour or may deny that it’s happening. This is why it is important that specialists ask both the person with Parkinson’s and their carer about any changes in behaviour.

What’s the evidence?

Impulsive and compulsive behaviour are a known side effect of some Parkinson’s medications. Although there are many estimates, the most comprehensive study to date shows that approximately 17% of people with Parkinson’s taking dopamine agonists and 7% of people taking other kinds of Parkinson’s drugs are affected by impulsive and compulsive behaviour.¹

The study shows that 3.5% of people taking Parkinson’s medication will develop compulsive sexual behaviour, 5.7% will develop compulsive shopping and 5% will develop pathological gambling.²

Research also shows that some people with Parkinson’s are more vulnerable to developing these side effects of drugs and need to be assessed when prescribing decisions are being made.

Impulsive and compulsive behaviour also continues to be an issue raised by people affected by Parkinson’s through our helpline and on our online forum.

There have also been a number of court cases where the impact of Parkinson’s medication on impulsive and compulsive behaviour has been recognised. A court in France awarded damages to a person with Parkinson’s who had developed a gambling addiction and hypersexuality which was found to be as a result of his Parkinson’s medication. In September 2008, a person with Parkinson’s was found not guilty by Oxford Crown Court after the court accepted that his offence was committed as a result of his prescription of dopamine agonists. During the trial a medical expert reported that ‘hypersexuality was indeed a common side effect [of the drug].’³

What is Parkinson’s UK is doing?

Through our campaigning, information resources, media work and professional education we are working with people affected by Parkinson’s, professionals and researchers to raise awareness of these side effects and mitigate the risks.

We have funded three research projects into impulsive and compulsive behaviour. More information can be found at: <http://www.parkinsons.org.uk/content/differences-brain-may-contribute-impulsive-and-compulsive-behaviour> and

¹ Weintraub et al (2010) ‘Impulse Control Disorders in Parkinson Disease’ *Arch Neurol* 67(5) 589-595

² Weintraub et al (2010) ‘Impulse Control Disorders in Parkinson Disease’ *Arch Neurol* 67(5) 589-595

³ Independent 12 September 2008. www.independent.co.uk/news/uk/home-news/paedophilia-blamed-on-teachers-medication-927095.html

<http://www.parkinsons.org.uk/content/managing-impulsive-and-compulsive-behaviour-parkinsons>

Information sheets for professionals and people affected can be downloaded from: www.parkinsons.org.uk/publications. There are films for professionals and people affected by Parkinson's at www.parkinsons.org.uk/icbresources

Support is available through our confidential free phone help line where nurses are experienced in talking about these issues. We also have trained volunteers with experience of impulsive and compulsive behaviour who can offer help via our peer support service (available through our helpline).

More information about how we are raising awareness of impulsive and compulsive behaviour can be found at: www.parkinsons.org.uk/icbresources

Please note: Anyone experiencing impulsive and compulsive and behaviour should not stop taking their medication without seeking advice from their specialist.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on impulsive and compulsive behaviour. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

Further information

Please contact the Professional Engagement and Education team. Tel: 020 7963 9336 or email professionals@parkinsons.org.uk

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