

IMPULSIVE AND COMPULSIVE BEHAVIOURS IN PARKINSON'S

**Treatments, therapies
and side effects**

Find out more about
these behaviours and
when to seek help

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IMPULSIVE AND COMPULSIVE BEHAVIOURS IN PARKINSON'S

Impulsive and compulsive behaviours are a possible side effect of some Parkinson's drugs. This information describes what they are, why they might happen and how to manage them.

In this information we use the term impulsive and compulsive behaviours to include all the types of behaviour you may experience. But you may also hear the phrase Impulse Control Disorder used to describe some of these behaviours. You can read about Impulse Control Disorder further on in this information.

Key points

- Not everyone who takes Parkinson's medication will experience impulsive and compulsive behaviours, so these side effects should not put you off taking your medication to control your symptoms
- Impulsive and compulsive behaviours can have a serious impact on the person affected and those around them so speak to your healthcare professional as soon you notice any changes

- Asking your specialist to make changes to your medication regime or adjust the doses that you take is the easiest way to control these behaviours

What are impulsive and compulsive behaviours?

People who experience impulsive and compulsive behaviours can't resist the temptation to carry out an activity – often one that gives immediate reward or pleasure.

Impulsive and compulsive behaviours happen when a person has an overwhelming urge to behave in a certain way. They will often carry out their behaviour repetitively as a way to reduce the worry or tension they get from their urge.

Some people continue to act in this way without thinking and even when they no longer get any pleasure or reward from the activity.

Speak to your GP, specialist or Parkinson's nurse as soon as you or your family or carer notice any change in behaviour.

Impulsive and compulsive behaviours that are more severe, are often categorised as Impulse Control Disorder.

In this information we use the term impulsive and compulsive behaviours to include Impulse Control Disorder too. But below we give examples of both.

Impulse Control Disorder

Addictive gambling

This is when someone can't resist the impulse to gamble, even though it may harm their family or personal finances.

Gambling is easier to do than ever before – especially online, on TV or on your phone. This means it may not always be obvious that someone is doing it.

Some people with Parkinson's who have developed an addiction to gambling have told us they might even steal money to gamble or to finance an expensive lifestyle.

Hypersexuality

This is a focus on sexual feelings and thoughts. Sexual impulses become more intense and might be felt at inappropriate times and towards people other than a partner. This can be really distressing for the person and those around them.

It may also result in an increase in using the internet to access explicit websites. This may happen in secret, perhaps in the middle of the night, when no one else would know. For example, it's now easier than ever to access porn on the web, and hide that you're watching it.

Some people may experience changes in sexual orientation or start wearing clothes usually worn by people

of the opposite sex. There's also a risk that someone will behave in a way that's socially unacceptable, or may even break the law.

Binge eating

This is when someone eats large amounts of food in a short period of time because they can't control their appetite, so they could gain a lot of weight.

People with this impulse may eat alone because they're embarrassed or feel guilty about the amount of food they're eating. They may also eat secretly at night.

Obsessive shopping

Some people may become obsessed with buying things. They will get an irresistible urge to buy more than they can afford or need. This can lead to financial problems. This problem is increasing because it's easier than ever to shop online these days, and for spending to creep up over time.

Other types of impulsive and compulsive behaviours

Punding

This is when someone does things such as continually handling and sorting objects. They may be fascinated with taking technical equipment apart or collecting a type of object. This behaviour can mean people don't get enough sleep. It can also cause social problems with family or at work.

If someone collects objects or takes machinery apart without knowing how to put it back together, it can also have a big financial impact, as they'll need to spend money to buy new objects or getting equipment repaired.

Some people also experience other behaviours such as compulsive singing, writing, smoking, reckless driving or walking around for no reason and with no purpose

Hobbyism

This is when someone has the compulsive urge to carry out a hobby such as cleaning, using the internet or doing crafts.

Hoarding

This is when someone feels that they must continue to keep items that they don't need. The thought of getting rid of the items may make someone feel upset.

Addiction to Parkinson's medication (dopamine dysregulation syndrome)

Some people with Parkinson's have a compulsion to take more medication than they need to control their symptoms because they are addicted to the way it makes them feel.

If a person is taking too much medication and their healthcare professional attempts to reduce it to the levels they're supposed to take, this may cause unpleasant feelings, anxiety and cravings. It may also cause reduced mobility.

A person may refuse to accept this, sometimes resulting in aggression, secret hoarding or requests for repeat prescriptions.

Remember that you may not realise you are increasingly taking more medication. So it's important that family members or carers know your prescribed doses so they can spot when you're taking too much.

Which type of drugs are linked to impulsive and compulsive behaviours?

Dopamine agonist medication, such as ropinirole, has been linked most strongly to impulsive and compulsive behaviours but you may experience this side effect because of other Parkinson's medication or deep brain stimulation, too.

What proportion of people with Parkinson's experience impulsive and compulsive behaviours?

It's difficult to find one number that answers this question. Research into impulsive and compulsive behaviours is ongoing.

Below we mention some key research.

A recent review of published research found that the reported proportion of people with Parkinson's who experience impulsive and compulsive behaviours varied a lot from 2.6% to 34.8%.

Some studies in specific groups of people have found that this number is higher. For example, a study of some younger people with Parkinson's reported that 58.3% experienced impulsive and compulsive behaviours.

The number of people who may experience impulsive and compulsive behaviours may vary in research because of:

- differences in research study design
- differences in the methods used to diagnose Impulse Control Disorder
- different social and cultural backgrounds amongst those participating in studies

People with Parkinson's may also be embarrassed about their behaviour and not report it to their healthcare professional. There may also be limited awareness of impulsive and compulsive behaviours and people may not think that there is a link to Parkinson's medications.

Most of the research we mention focuses on certain impulsive and compulsive behaviours which are categorised as Impulse Control Disorder. Find out more about this in our

first section about what impulsive and compulsive behaviours are.

What might cause impulsive and compulsive behaviours?

Our understanding of these issues in Parkinson's is still emerging. However, they might be related to dopamine stimulation in the brain.

Dopamine is the chemical messenger in the brain affected in Parkinson's. It controls movement and Parkinson's medication helps to ease movement symptoms and restore dopamine levels. But taking Parkinson's medication can also overstimulate other parts of the brain too, which can lead to impulsive and compulsive behaviours.

Some people may be more likely to develop these behaviours, for example:

- younger people with Parkinson's
- people who have had Parkinson's for a long time
- people who have issues with movement (known as motor complications)
- smokers
- people with a history of psychiatric symptoms
- people with a family history of gambling or alcohol abuse

Speak to your GP, specialist or Parkinson's nurse about impulsive and compulsive behaviours

Not everyone who takes Parkinson's medication will experience these behaviours so it should not put you off taking your medication

to control your symptoms. However, make sure you get help as soon as possible if there are any issues.

Asking your specialist to make changes to your medication regime or adjusting the doses that you take is the easiest way to control impulsive and compulsive behaviours. So, if you or the person you care for is experiencing this side effect, tell your healthcare professional as soon as possible before it creates large problems.

Clinical guidelines

Clinical guidelines say professionals should give you, your family and carers information about the possibility of impulsive and compulsive behaviours when you start taking drugs that may cause it. This should include information about the possible types of behaviours, how a person might hide their behaviour and who to contact if you have concerns.

The guidelines also say professionals should discuss whether you're experiencing any impulsive or compulsive behaviours regularly at review appointments.

As a family member, friend or carer of someone with Parkinson's, how do I spot signs of impulsive and compulsive behaviours?

Often, people who experience impulsive and compulsive behaviours may not realise they have a problem. So, if you're a carer or a family member and you notice any changes in behaviour, talk to the person with Parkinson's and get support from their healthcare professional.

It's important to understand that many behaviours are kept secret or may not be

apparent even to close family and friends.

The person experiencing behaviour changes may or may not experience distress, and possibly may not realise the effects their behaviour will have.

NHS guidelines say that healthcare professionals, carers and family members of people with Parkinson's need to monitor behaviour over a long period of time. This is because these behaviours can develop some time after treatment is introduced. In some cases, this can be after years of treatment without any problems.

If you're concerned about someone with Parkinson's, look out for any of the following signs:

- Have they recently put on weight? There may be a number of reasons for this, but you might want to look for the signs of binge eating. Someone

may be eating large quantities of food, even when they're not hungry, in a short period of time and in private. They may be feeling guilty about their behaviour

- Are they being more protective than usual about their finances?
- Are they being more secretive, perhaps with phone calls or their use of the internet?
- Have they started collecting or organising certain objects?
- Have you noticed them carrying out some tasks repeatedly?
- If the person with Parkinson's is your partner, have you noticed an increase in their sex drive or a change in their sexual behaviour, either towards you or anyone else?
- Are they going shopping more often than usual?
- Are they more restless and irritable than usual?
- Are they spending more money, or have they started to lead a more expensive lifestyle?
- Are they spending more time than usual on their computer, phone or tablet (perhaps on shopping or gambling websites, or websites with sexual content)? This may be during the night or the early hours of the morning, so you may not even be aware this is happening. Online services have made it much easier to engage in compulsive shopping, gambling and sex than it used to be.
- Are they taking more of their Parkinson's medication than they should?
- Have you noticed an increase in any aggressive behaviour?

It can be upsetting to realise that these things may be happening to someone you love, but remember that these behaviours are triggered by their Parkinson's treatment.

Practical ways to manage impulsive and compulsive behaviours

If you think you're experiencing impulsive and compulsive behaviours, the first step is to speak to your specialist or Parkinson's nurse. It can be upsetting to realise this is happening to you, so it shows strength of character to get medical advice. Remember, your behaviour doesn't reflect badly on you.

It may be embarrassing and you may feel uncomfortable talking to a healthcare professional about the difficulties you're having. But remember they'll have

spoken to others with similar problems before and everything you tell them will be treated confidentially.

If you find it difficult to talk about, try writing your questions down and giving them to the healthcare professional you're seeing. If you feel comfortable, you may want to attend appointments with your partner, carer, friend or relative, so you can discuss the issues together.

You can also speak anonymously to an adviser on our free, confidential helpline **(0808 800 0303)**. Our specialist helpline nurses have a lot of experience of talking about this issue.

You may also find other practical things useful, such as asking a trusted family member to keep your credit cards safe, setting up internet blocks on gambling or explicit websites and having voluntary 'bans' from bookmakers.

Treatment for impulsive and compulsive behaviours

Treatment can involve reducing your daily dose of Parkinson's medication, or changing a dopamine agonist prescription to levodopa or another type of medication.

Clinical guidelines say your healthcare professional should talk with you about the benefits and disadvantages of changing your Parkinson's treatment. They should also make any changes gradually, monitoring you for changes in behaviour and withdrawal symptoms. They should offer you psychotherapy if changing drugs is not completely effective too.

Don't stop taking or change your Parkinson's medication without the advice of your specialist or Parkinson's nurse. Any changes have to be made slowly and gradually and should always be carried out and reviewed by a specialist, because of the risk of side effects and withdrawal symptoms.

You should also talk to your specialist or Parkinson's nurse about having a general mental health assessment with a qualified professional. This is because certain problems, such as depression, may increase the development of impulsive and compulsive behaviours.

For more support you can take this information to your appointment to discuss with your healthcare professional. Our Parkinson's local advisers can also help in your local area. You can find their contact details at the end of this information.

Medicines and Healthcare Products Regulatory Authority

Side effects from Parkinson's drugs can take many forms and our helpline deals with lots of enquiries related to side effects each year.

You can also report any side effects to the Medicines and Healthcare Products

Regulatory Authority (MHRA), the government body responsible for ensuring medicines work and are safe. To do so, you should complete a Yellow Card form, available from your pharmacist, GP, specialist or via the Yellow Card hotline **(0808 100 3352)**.

You can also complete this form online, or download and print it out from **www.yellowcard.mhra.gov.uk**

More information and support

While some of the side effects discussed here can be embarrassing, it's important to seek help if you recognise any of these issues in yourself or someone you know.

The organisations listed on the next page offer a sensitive and professional service.

Gamcare

This organisation provides support, information and advice to anyone experiencing a gambling problem. Its website offers the option to talk live online with a trained adviser, or to use its forum and chat-room to speak to others going through a similar experience.

0808 802 0133

www.gamcare.org.uk

Action against Medical Accidents (AvMA)

This independent charity has a team of medically and legally trained caseworkers providing free and confidential advice to people who have been affected by a medical accident. Its website includes a link to finding a solicitor.

0845 123 2352

www.avma.org.uk

College of Sexual and Relationship Therapists

A charity whose professional members offer sexual and relationship therapy.

020 8543 2707

info@cosrt.org.uk

www.cosrt.org.uk

Relate

Relate offers counselling for people with sexual or relationship problems.

0300 100 1234

www.relate.org.uk

If debt has become a problem, these agencies may be able to help. Please note, these agencies do not work directly with Parkinson's UK, but have a national reputation.

National Debtline

A helpline that provides free, confidential and independent advice on

how to deal with debt problems.

0808 808 4000

www.nationaldebtline.org

StepChange Debt Charity

A debt charity that offers free, anonymous advice.

0800 138 1111

www.stepchange.org

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

Parkinson's UK information and support

You can read our most up-to-date information at **parkinsons.org.uk**. You can order printed information by calling **0330 124 3250** or visiting **parkinsons.org.uk/orderingresources**

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email **hello@parkinsons.org.uk**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **parkinsons.org.uk/forum**

Thank you

Thank you very much to everyone who contributed to or reviewed this information.

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email **feedback@parkinsons.org.uk**, or write to us at Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do.

There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Care team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**

Thank you.

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Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–6pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk

Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ



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