

Impulsive and compulsive behaviours in Parkinson's

Treatments, therapies and side effects

Find out more about these behaviours and when to get help for them



Impulsive and compulsive behaviours in Parkinson's

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

Key points

- Not everyone who takes Parkinson's medication will experience impulsive and compulsive behaviours. These side effects shouldn't put you off taking your medication.
- Impulsive and compulsive behaviours can have a serious impact on a person with Parkinson's and those around them. Speak to your healthcare professional as soon as you notice any changes.
- The best way to manage these behaviours is by talking to your specialist or Parkinson's nurse. They can make changes to your medication, such as adjusting your routine or doses, which can help you control these symptoms.

What are impulsive and compulsive behaviours?

Impulsive behaviour is when someone can't resist the urge to carry out an activity - often one that gives instant reward or pleasure. They'll quickly act on this urge without thinking about the possible negative impacts it might cause. For example, buying something expensive that they can't afford.

Impulsive behaviour may negatively impact the person and those around them. It may lead them to legal or money problems.

In compulsive behaviour, a person has a strong urge to act in a certain way, often repeatedly. They'll often carry out this behaviour to help reduce the worry or tension they get from their urge. For example, eating large amounts of food even when they're not hungry.

Speak to your specialist or Parkinson's nurse as soon as you or your family, or the person who supports or cares for you, notices any change in behaviour.

Impulse control disorder

Impulsive and compulsive behaviours that are more severe are often called 'impulse control disorders'.

People with Parkinson's can experience the following impulse control disorders.

Addictive gambling

This is when someone can't resist the impulse to gamble, even though it may cause money problems or harm their relationships with loved ones.

For example, if someone loses a lot of money gambling, it may upset their partner and cause arguments.

Some people with Parkinson's have told us they might even steal money to gamble, or to pay for an expensive lifestyle.

There are different ways to gamble, such as using betting shops, placing bets online, or using mobile phone apps. If someone uses their phone to gamble, it may not always be obvious they're doing it.

Hypersexuality

This is when a person has unusually strong sexual thoughts and urges that they can't control. These might be felt at inappropriate times and towards people other than a partner. This can be distressing for the person and those around them.

It may also lead them to use porn websites or sex chat lines. This may happen in secret, perhaps in the middle of the night, when no one else would know.

Some people may experience changes in their sexuality. Someone may also behave in a way that's not socially acceptable, or may even break the law.

Binge eating

This is when someone eats a lot of food in a short period of time, and isn't able to stop, even when they may feel full.

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

Obsessive shopping

Some people may become obsessed with buying things from shops or online. They'll get an urge that they can't control to buy more than they need or can afford. This can lead to issues with money. It can also impact someone's mental health.

Other types of impulsive and compulsive behaviours

Punding

This is when someone repeatedly carries out an activity that has no goal or purpose. This usually includes handling and sorting objects. The person may be fascinated with taking electronic equipment apart or collecting a type of object, for example. People may stay up all night to carry out this behaviour, which can affect sleep. It can also cause social problems with family or at work.

Punding can also seriously affect someone's finances. For example, they might have to replace or repair electronic items they've taken apart.

Some people also carry out other behaviours with no purpose, such as compulsive smoking, driving or walking, or using the internet too much.

Hobbyism

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

Hobbies are usually healthy habits that people enjoy in their spare time. But in hobbyism, someone will spend an unusually long amount of time focusing on an activity or interest. This can negatively impact their personal life. For example, someone might be so fixated on their hobby, they repeatedly miss meals that they would usually have with their family.

Hoarding

This is when someone repeatedly collects and stores items that they don't need. The thought of getting rid of the items may make them feel upset.

People who hoard usually store these items in an untidy or disorganised way. This can disrupt everyday life and make the person feel distressed. It can also negatively affect their loved ones.

Dopamine dysregulation syndrome

Some people with Parkinson's may have a strong urge to take more medication than they need. This is because they're addicted to the way it makes them feel. This is called dopamine dysregulation syndrome.

People who experience 'off' periods may also take more medication than they need. They will do this to avoid the unpleasant feelings they get from their Parkinson's symptoms.

'On/off' periods happen when someone's Parkinson's medication doesn't work as well as it used to. Because of this, their symptoms will return before their next dose is due. This is known as the 'off' period. When a person's symptoms are well controlled and their medication is working well, this is known as the 'on' period.

If a person is taking too much medication, their healthcare professional will encourage them to reduce it to their normal dose. The person may resist or refuse to reduce their medication because they think they need a higher dose. They may also secretly hoard medications or hide them so they can get more.

You may not realise you're increasingly taking more medication. So it's important that family members or anyone who cares for you know your prescribed doses. This can help them spot if you're taking too much.

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

Parkinson's medication can cause impulsive and compulsive behaviours. Dopamine agonist medications, including ropinirole and pramipexole, have been linked most strongly to impulsive and compulsive behaviours.

Ropinirole and pramipexole are the generic names for dopamine agonists. You may know your medication by a brand name which is often more obvious on the packaging. You can also check for the generic name on the leaflet that comes with your medication.

You may also experience impulsive and compulsive behaviours if you have had deep brain stimulation (DBS).

How many people with Parkinson's develop impulsive and compulsive behaviours?

This is hard to answer because studies on this area have shown very different results. But research into Parkinson's and impulsive and compulsive behaviours is still being carried out.

People with Parkinson's may be embarrassed about their behaviour and not report it to their healthcare professional. They may also not know what impulsive and compulsive behaviours are. Because of this, people may not think it could be linked to Parkinson's medications.

Some key studies have given a different picture of how many people with Parkinson's may experience impulsive and compulsive behaviours.

This includes a recent review of several studies, which found that the percentage of people with Parkinson's who experience impulsive and compulsive behaviours varies from 3.5–43%.

Some other studies have found that this number is higher in specific groups of people. For example, a study of some younger people with Parkinson's found that nearly 60% experienced impulsive and compulsive behaviours.

Who's most at risk of impulsive and compulsive behaviours?

Our understanding of these behaviours in Parkinson's is still developing. However, they might be linked to dopamine stimulation in the brain.

People with Parkinson's don't have enough of the chemical dopamine because some of the nerve cells in their brain have stopped working. This causes Parkinson's symptoms, including problems with movement.

Parkinson's medication helps to increase dopamine levels and ease movement symptoms. But Parkinson's medication can also cause too much stimulation in other parts of the brain. This can lead to impulsive and compulsive behaviours.

Some people may be more likely to develop these behaviours. This includes:

- if you're male
- younger people with Parkinson's
- those who've had Parkinson's a long time
- people who experience wearing off with their medication, which can sometimes cause involuntary movements (dyskinesia)
- people who smoke
- people with a history of mental health symptoms, such as depression or anxiety
- those with a family history of gambling or alcohol abuse

Getting help for impulsive and compulsive behaviours

Not everyone who takes Parkinson's medication will experience these behaviours. It shouldn't put you off taking your medication to control your symptoms. But make sure you get help as soon as possible if there are any issues.

Asking your specialist to make changes to your medication routine is the most effective way to control impulsive and compulsive behaviours. They may also adjust the doses you take.

Some people who experience these behaviours may not realise they have a problem. But people around them might notice there's an issue, including loved ones or those who care for them. If you're worried about someone with Parkinson's, see the 'Advice for family members, loved ones and those who care for people with Parkinson's' section.

Getting the right information

Your specialist or Parkinson's nurse should give you, your family and anyone who cares for you, information about impulsive and compulsive behaviours. 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.

This should happen when you're prescribed medication that may cause impulsive and compulsive behaviours.

Your specialist will discuss whether you're experiencing any impulsive or compulsive behaviours at review appointments. Being as honest as possible with your specialist or Parkinson's nurse will help you get the right support if you need it.

Your specialist or Parkinson's nurse will also monitor you if you have a pre-existing habit. For example, if you've always enjoyed shopping, but this activity then increases beyond your control.

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. You may feel embarrassed or uncomfortable about this. But remember, they have plenty of experience in treating these issues, and everything you tell them will be kept confidential.

If you find it difficult to talk about, try writing your questions down and giving them to your specialist. If you feel comfortable, you may want to attend appointments with a loved one or the person who supports or cares for you. You might find it helpful to 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 in 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, or blocking access to gambling or porn websites. It's also possible to ask for a voluntary ban from betting shops.

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.

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. This will allow them to monitor you for changes in behaviour and withdrawal symptoms.

There is some evidence that psychotherapy, such as cognitive behavioural therapy (CBT), can help if changing drugs isn't completely effective.

It's important you 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. They should also be carried out and reviewed by a specialist. This is because there's a risk of side effects and withdrawal symptoms.

You should also talk to your specialist, Parkinson's nurse or someone you trust about how you're feeling. This is because certain problems, such as depression, may increase the risk of impulsive and compulsive behaviours.

For more support, you can take this information to your appointment to discuss with your Parkinson's specialist.

Medicines and Healthcare Products Regulatory Authority (MHRA)

The MHRA is a government organisation responsible for making sure medicines work and are safe. You can report any side effects from your medicine to them by completing a Yellow Card form. These are available from your pharmacist, GP or specialist, or by calling **0800 731 6789**.

You can also complete this form online at **yellowcard.mhra.gov.uk**

Advice for family members, loved ones and those who care for people with Parkinson's

Often people who experience impulsive and compulsive behaviours may not realise they have a problem.

But you may have noticed changes in the person's behaviour, which might worry you. If so, you should talk to them about it and get support from their specialist or Parkinson's nurse.

It's important to understand that some people with Parkinson's may keep certain behaviours secret, or they may not be obvious even to close family and friends. The person may not experience distress, or realise their behaviour is affecting those around them.

These behaviours can develop some time after a person starts taking Parkinson's medication. In some cases, this can be after years of treatment without any previous problems.

If you're concerned about someone's behaviour, it may help to look out for the following signs.

- Are they taking more of their Parkinson's medication than they should?
- Have they recently put on weight? There may be different reasons for this, but you might want to look for signs of binge eating. This includes eating large amounts of food in a short period of time, even when they're not hungry. They may feel guilty about their behaviour and may eat in private.
- Are they being more protective than usual about their finances?
- Are they being more secretive, perhaps with phone calls or their internet use?
- 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 easily annoyed than usual?

- Are they spending more money, or have they started living 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 early hours of the morning.
- Have you noticed them becoming more aggressive or angry?

It can be upsetting if someone you love is experiencing these issues.

But these behaviours can be managed with the right support from their specialist or Parkinson's nurse.

More information and support

It's important to speak to your healthcare professional if you or someone around you begins to notice changes in your behaviour.

The organisations below can support anyone, not just people with Parkinson's, who are experiencing specific impulsive or compulsive behaviours.

British Association for Cognitive and Behavioural Psychotherapies (BABCP)

The organisation has a list of registered cognitive behavioural therapists.

0330 320 0851

www.babcp.com

Gamcare

A charity that provides information and support to anyone experiencing a gambling problem. You can speak to a trained adviser via their free helpline or online chat service. The website also has a forum and group chatroom where you can speak to others going through a similar experience.

0808 802 0133

www.gamcare.org.uk

GambleAware

A charity that offers information and support for issues related to gambling. This includes details of organisations in your area that can offer support. GambleAware also shares a free helpline and online chat service with GamCare.

0808 802 0133

www.begambleaware.org

College of Sexual and Relationship Therapists

This is the UK's professional organisation for therapists and counsellors specialising in sexual and relationship issues. Their website has a 'find a therapist' tool, which you can use to find trained therapists in your area.

020 8106 9635

info@cosrt.org.uk

www.cosrt.org.uk

Relate

Relate offers counselling for people with sexual or relationship problems, including hypersexuality.

0300 100 1234

www.relate.org.uk

In Scotland

0345 119 2020

www.relationships-scotland.org.uk

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

Whatever your journey with Parkinson's, you're not alone.

From the moment you or someone you care about is diagnosed, we have information and support for you.

Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers. We've got information and advice on all aspects of living with Parkinson's.

Get help managing your diagnosis. Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

Read our up to date, reliable health information. Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

Find ways to get active, stay active and live well with Parkinson's. Whatever your fitness level, we'll help you find the right activities for you.

Connect with other people with Parkinson's, families, friends and carers. Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

Find out more

- Call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk** to speak to an expert adviser.
- Visit **parkinsons.org.uk/information-and-support** to read our information or find support that's local to you.
- Call **0330 124 3250** or visit **parkinsons.org.uk/order-print-booklets** to order free printed information.

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, 50 Broadway, London, SW1H 0BL.

If you'd like to find out more about how we put our information together, or be part of the team that reviews our health content, please contact us at **healthcontent@parkinsons.org.uk** or visit our website at **parkinsons.org.uk/health-content**.

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.



We're Parkinson's UK,
the charity that's
here to support every
Parkinson's journey.
Every step of the way.

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

Parkinson's UK, 50 Broadway, London SW1H 0DB



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