Impulsive and compulsive behaviour in Parkinson’s

Impulsive and compulsive behaviour is a possible side effect of some Parkinson’s drugs. Only a relatively small number of people experience this, but it can have a big impact on the person affected and those around them.

This information sheet looks at the different types of impulsive and compulsive behaviour, why it happens, how to manage the risk of this behaviour and how it can be treated.

What is impulsive and compulsive behaviour?

Impulsive behaviour is when a person can’t resist the temptation to carry out certain activities. These are often activities that give an immediate reward or pleasure, such as gambling, eating or shopping, or an increase in sexual thoughts and feelings, or punding (see page 3 to find out more). Some people may experience more than one of these behaviours.

Some people may do an activity without giving any thought to the future or to long-term consequences. For example, someone who has the impulse to shop may buy a new item of clothing, even if they can’t really afford it.

This behaviour may lead to harmful social, financial or legal consequences.

Compulsive behaviour is when a person has an overwhelming drive to act in a certain way, often repetitively, to reduce the worry or tension they get from their urge. Some people continue to act in this way, even if they no longer get any pleasure or reward from the activity.

In most cases, this behaviour is out of character for the person experiencing it.
My mother became obsessed with moving items from A to B with no purpose and to a place they did not belong. I never tried to stop her from moving things. I managed it every day by giving her a specific tidying task, while I returned things to their correct place. I soon learnt never to leave my keys lying around!

Rachel, whose mum had Parkinson’s

How does this relate to Parkinson’s?
Impulsive and compulsive behaviour is related to dopamine levels in the brain. Dopamine is the chemical messenger in the brain that is affected in Parkinson’s. As well as helping to control movement and balance and walking, dopamine also plays a big role in the part of the brain that controls reward and motivation. This is important, as people affected by impulsive and compulsive behaviour are driven or motivated to do something that gives them an instant reward.

Medicine and behaviour
Many Parkinson’s drugs – particularly dopamine agonists and, in some cases, levodopa – have been linked to these types of behaviour, although it is not exactly clear how the medications cause the changes in behaviour.

Research has shown that around 17% of people with Parkinson’s who take dopamine agonists experience impulsive and compulsive behaviour.

For a small number of people, other types of Parkinson’s medications, in particular levodopa, have also been shown to have similar side effects. The research suggests that 7% of people who take these other kinds of medication are affected.

Researchers think that because medications affect people in different ways, some people may be more likely to experience this behaviour.

Evidence suggests that you may be more likely to experience impulsive and compulsive behaviour if you are:

- male
- a younger person with Parkinson’s
- a single person who lives alone
- a smoker
- someone with a history of addictive behaviour
- someone who has a family history of gambling or alcohol abuse

Remember that not everyone will experience this behaviour, so it should not put you off taking your medication. But we do encourage you to talk to your Parkinson’s nurse or specialist about these side effects (see page 7).

How serious the changes in a person’s behaviour are will vary in how serious they are. Some changes may be helpful rather than negative. For example you may experience a renewed or increased interest in hobbies or sex. Losing interest in hobbies and sex
are symptoms of apathy, which can also affect people with Parkinson’s. If you feel you are experiencing apathy, speak to your GP, specialist or Parkinson's nurse.

**What types of impulsive and compulsive behaviour are there?**

The following are common types of impulsive and compulsive behaviour:

**Addictive gambling**
This is when someone can’t resist the impulse to gamble, even though it could have a bad effect on their family or personal finances. Gambling is easier to do than ever before – especially online – so it may not always be obvious that someone is doing this.

Some people who have developed an addiction to gambling have told us they would steal money in order 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 this is happening.

Some people may experience changes in sexual orientation or start wearing clothes usually worn by people of the opposite sex.

There is also a risk that someone will behave in a way that is socially unacceptable, or may even break the law.

**Binge eating**
Someone may eat 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.

**Obsessive shopping**
Some people may become obsessed with buying things. They will get an irresistible need to buy more than they can afford or need. This can lead to financial problems.

**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 will need to spend money to buy new objects or replace dismantled appliances or other equipment.

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

“However humiliating or undignified this behaviour feels, you can talk to a health professional – they will have heard it all before. They won’t be shocked or make judgments about you.”

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Tracey Ward, Parkinson’s nurse
Addiction to Parkinson’s medication
When someone has the compulsion to take more medication than is needed to control their Parkinson’s symptoms, this is known as dopamine dysregulation syndrome. This is a type of impulsive and compulsive behaviour.

If someone is taking too much levodopa, this can lead to more side effects, such as severe involuntary movements (dyskinesia) or hallucinations.

If a person is taking too much medication and their healthcare professional attempts to reduce it to the levels they are supposed to take, this may cause unpleasant feelings, anxiety and cravings. A person may refuse to accept this, sometimes resulting in aggression, secret hoarding or requests for repeat prescriptions.

Some people who are switched to levodopa-based treatment after experiencing impulsive and compulsive behaviour on other medication may develop dopamine dysregulation syndrome. So it is important your treatment is monitored by your healthcare professional.

When should I talk to my GP, specialist or Parkinson’s nurse about these potential side effects?
If you are already taking Parkinson’s medication don’t worry, but we do encourage you to talk to your specialist about these potential side effects, especially if you have a family history of these types of behaviour. This may give you some peace of mind and will help you monitor any potential changes in behaviour together.

It is important that you are assessed for any potential risk of impulsive and compulsive behaviour by your healthcare professional before you start taking your medication for Parkinson’s. This can be done using the checklist on page 9, which can also be used to monitor treatment over time and to check for any changes in behaviour.

As a family member, friend or carer of someone with Parkinson’s, how do I spot signs of impulsive and compulsive behaviour?
Sometimes people who experience impulsive and compulsive behaviour may not realise they have a problem. So if you are a carer or a family member and you notice any unusual behaviour, talk to the person with Parkinson’s and seek support from your healthcare professional.

It is important to understand that many behaviours are kept secret, or may not be apparent even to close family and friends. The person experiencing this behaviour may or may not experience distress, and possibly, may not realise the effects their behaviour will have.

“My husband’s Parkinson’s progressed quite rapidly after his diagnosis aged 43, and it wasn’t long before he was put on Parkinson’s medication that is now, thankfully, very rarely used. There was no way that I could be prepared for what we went through next. His behaviour became out of control. He bought clothes he didn’t need, huge amounts of food – he just couldn’t stop buying things.

But things only got worse as he began putting himself in dangerous situations. He was taking drugs, seeing sex workers and going out all night. Our money was completely squandered. Life became a nightmare.”

Elaine, whose ex-husband has Parkinson’s
NHS guidelines state 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 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 spending more money, or have they started to lead a more expensive lifestyle?

- Are they spending more time than usual on their computer (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.

- Are they taking more of their Parkinson’s medication than they should?

- Have you noticed an increase in any aggressive behaviour?

Some people may be more likely to experience this behaviour, including people who have a family history of any of the above, and people who fit the risk factors shown on page 2.

It can be upsetting to realise that this may be happening to someone you love, but remember that this behaviour doesn’t reflect badly on them or you.

“Parkinson’s medications do a lot of good, when they are monitored. If you’re aware that you, or a friend or relative, may be experiencing impulsive and compulsive behaviour, use the information available. Don’t live in denial. Speak with a healthcare professional. I don’t want anyone else to go through what I’ve been through with impulsive and compulsive behaviour.”

Stephen, diagnosed in 2001
What should I do if I’m experiencing impulsive and compulsive behaviour, or I think someone else is?

People with Parkinson’s, carers, family members and friends should be alert for any changes in behaviour, and work with healthcare professionals to monitor this. The checklist on page 9 may help during your appointments.

If you think you’re experiencing this behaviour, the first step is to speak to your specialist or Parkinson’s nurse (if you have one – see page 7). It can be upsetting to realise this is happening to you, so it shows strength of character to seek medical advice. Remember, this behaviour does not reflect badly on you.

Some of this behaviour may be embarrassing and you may feel uncomfortable talking to a healthcare professional about the difficulties you are having. But remember they will 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.

Can impulsive and compulsive behaviour be controlled?

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

We don’t advise anyone to stop taking or to change their Parkinson’s medication without the advice of their 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. Dopamine agonist withdrawal syndrome can happen when someone stops taking dopamine agonists very suddenly. It can lead to symptoms such as depression, anxiety or pain.

You may also find other practical measures 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.

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 behaviour. Treating mood problems may also help to control the behaviour.

Find out more: our Impulsive and compulsive behaviour in Parkinson’s information and monitoring tool can help you talk about this issue with your specialist or Parkinson’s nurse.

You can also complete and take along the checklist on page 9, to discuss with your healthcare professional.

More information and support

To watch a film explaining impulsive and compulsive behaviour, find out more about this side effect and read people’s experiences, visit parkinsons.org.uk/icbsupport
Parkinson's nurses
Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at parkinsons.org.uk/nurses

Information and support from Parkinson’s UK
You can call our free confidential helpline for general support and information. Call 0808 800 0303 (calls are free from UK landlines and most mobile networks) or email hello@parkinsons.org.uk. We run a peer support service if you’d like to talk on the phone with someone affected by Parkinson’s who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our local information and support workers, who give one-to-one information and support to anyone affected by Parkinson’s. They can also provide links to local groups and services.

We also have a self-management programme for people with Parkinson’s, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you visit parkinsons.org.uk/selfmanagement

Our website parkinsons.org.uk has a lot of information about Parkinson’s and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at parkinsons.org.uk/localtoyou

You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.

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
Useful contacts
While some of the side effects discussed here can be embarrassing, it is important to seek help if you recognise any of these issues in yourself or someone you know. The organisations listed below offer a sensitive and professional service.

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

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

StepChange Debt Charity
A debt charity that offers free, anonymous advice.
0800 138 1111
www.stepchange.org

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
Impulsive and compulsive behaviour checklist

Type of Parkinson’s medication taken

Have you discussed the possible side effects of this medication with your healthcare professional? Yes ☐ No ☐

Have you discussed the following possible side effects before starting medication or while monitoring treatment?

- Gambling ☐ Yes ☐ No ☐
- Internet usage ☐ Yes ☐ No ☐
- Binge eating ☐ Yes ☐ No ☐
- Compulsive shopping ☐ Yes ☐ No ☐
- Sex drive or change in sexual behaviour ☐ Yes ☐ No ☐
- Repetitive activity or punding ☐ Yes ☐ No ☐

Do you have a personal history of any of the above?

Do you have a personal history of drug or alcohol misuse?

Do you have a family history of any of the above?

Have you discussed the potential side effects with close friend, relative or partner? Yes ☐ No ☐
Thank you
Thank you very much to everyone who contributed to or reviewed this information sheet:

Dr Graeme MacPhee, Consultant, Medicine for the Elderly, Southern General Hospital, Glasgow, and Honorary Clinical Senior Lecturer, School of Medicine, University of Glasgow

Gillian Carey, Parkinson’s Disease Nurse Specialist, St Peter’s Hospital, Chertsey

Thanks also to our information review group and other people affected by Parkinson’s who provided feedback.
Impulsive and compulsive behaviour in Parkinson's (2015)

If you have comments or suggestions about this information sheet, we’d love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to Editorial and Creative Services, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ. Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

☐ I have Parkinson's. When were you diagnosed? ..............................................................................................................................................................
☐ I'm family/a friend/a carer of someone with Parkinson's
☐ I'm a professional working with people with Parkinson's

Where did you get this information sheet from?
☐ GP, specialist or Parkinson's nurse ☐ Information and support worker
☐ Parkinson's UK local group or event ☐ Ordered from us directly
☐ Our website ☐ Other ..............................................................................................................................................

How useful have you found the information sheet? (1 is not useful, 4 is very useful) ☐ 1 ☐ 2 ☐ 3 ☐ 4
Have you found the publication easy to read/use? ☐ Yes ☐ No

Has this resource given you information that might help you manage your condition better?
☐ NA ☐ It hasn't helped ☐ It has helped a little ☐ It has helped a lot

What aspects did you find most helpful? ...........................................................................................................................................................................................
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Were you looking for any information that wasn't covered?
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Do you have any other comments?
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If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we’ll be in touch.

☐ Membership ☐ Information review group (who give us feedback on new and updated resources)

Name.................................................................................................................................................................................................
Address................................................................................................................................................................................................
Telephone................................................................. Email

What is your ethnic background? ☐ Asian/Asian British ☐ Black/Black British ☐ White
☐ Mixed/multiple ethnic backgrounds ☐ Other (please specify).................................................................................................................................................................................................................................................................
We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

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 Services team on 020 7932 1303 or visit our website at parkinsons.org.uk/support. Thank you.

Parkinson's UK
Free* confidential helpline 0808 800 0303
Monday to Friday 9am–8pm, Saturday 10am–2pm. Interpreting available.
Text Relay 18001 0808 800 0303
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk
* calls are free from UK landlines and most mobile networks.

How to order our resources
0845 121 2354
resources@parkinsons.org.uk
Download them from our website
at parkinsons.org.uk/publications

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

References for this information sheet can be found in the Microsoft Word version at parkinsons.org.uk/publications