

Impulsive behaviour in restless legs syndrome (RLS) – ropinirole, pramipexole, and rotigotine

Impulsive behaviour is a possible side effect of some medicines used in the treatment of RLS. The purpose of this leaflet is to provide you with some information about impulsive behaviours, why it happens and how to recognise and manage this behaviour. If you have any questions or concerns, please speak to a doctor or nurse caring for you.

What type of medicines are ropinirole, pramipexole and rotigotine?

These medications belong to a group of medicines called dopamine agonists (chemicals which activate areas in the brain that produce dopamine). Dopamine is a chemical which helps to regulate movement and mood.

RLS seems to be caused by a dopamine shortage in the brain, resulting in some of the uncomfortable sensations you may experience in your legs or other parts of your body.

Ropinirole and pramipexole are tablets which are taken orally, up to three hours before bedtime. Rotigotine is a patch which is applied to alternating sites of skin daily, to deliver a specific dose of medication through the skin and into the bloodstream. The patch should be applied to clean, dry, intact healthy skin on the abdomen, thigh, hip, side, back, shoulder, or upper arm. Reapplication to the same site within 14 days should be avoided. Rotigotine patches should not be placed on skin that is red, irritated or damaged.

These three medications work similarly, although patients often respond differently, which may result in your doctor trying different medications to find the most suitable one for you.

Dopamine agonists will not work for everybody and they also have several common side effects. An uncommon, but important, side effect is impulsive types of behaviour.

What is impulsive behaviour?

Impulsive behaviour is when a person cannot resist the temptation to undertake certain activities, and is related to dopamine levels in the brain. As well as helping to control movement, balance and walking, dopamine also works on the part of the brain that controls reward and motivation. This is

important because people affected by impulsive behaviour are driven or motivated to do something which gives them an instant reward.

Examples of how this behaviour can be expressed include, but are not limited to, the following:

- gambling
- obsessive shopping – a preoccupation with buying things
- binge eating
- hypersexuality – an increased focus on sexual feelings and thoughts

Medication can affect people in different ways, therefore some people may be more likely to experience this behaviour. It is thought that you may be more likely to experience impulsive behaviour if you are:

- male
- a single person living alone
- a smoker
- someone with a history of addictive behaviour
- someone who has a family history of gambling or alcohol abuse

It is important to remember that not everyone will experience this type of behaviour, so it should not discourage you from taking your medicine. Remember that some changes may be helpful rather than negative, for example you may develop an increased or renewed interest in hobbies.

We do advise you to seek help immediately if you experience these side effects, as it can have a significant impact on the you and those around you.

This behaviour may lead to harmful social, financial or legal consequences, therefore it is important that you are assessed for any potential risk of impulsive behaviour by your doctor before you start taking your medication. A checklist can be completed for this purpose, which can also be used to monitor treatment and assess any behavioural changes over time.

How do I spot the signs of impulsive behaviour?

Sometimes people who experience impulsive behaviour may not realise they have a problem. If you are a carer or a family member and you notice any unusual behaviour, talk to the person and seek support from your doctor or pharmacist.

It is important to remember that many behaviours are kept secret and may not be obvious to close family and friends. Such behaviours may also develop years after treatment has started, so we need to ensure that the behaviour of the person taking these medicines is monitored over a long period of time.

If you are concerned about someone, look out for the following signs:

- Have they recently put on weight (look for signs of binge eating, for example, eating large quantities of food, even when they are not hungry, in a short period of time, and in private)?
- Are they being more protective than usual about their finances?
- Are they being more secretive, either with phone calls or use of the internet?
- Are they spending more time than usual on the computer, usually during the night or early hours of the morning (perhaps on gambling or shopping websites)?
- If the person 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?
- Are they spending more money, or have they started to lead a more expensive lifestyle?
- Have you noticed an increase in any aggressive behaviour?

What should I do if I am experiencing impulsive behaviour?

If you think that you are experiencing this behaviour, please speak to your doctor or pharmacist as soon as possible. It may be upsetting to realise this is happening to you, and you might feel uncomfortable or embarrassed talking about it, but remember that this is a side effect of the medicine which you have been prescribed, and your doctor or pharmacist will have spoken to others who have suffered similar problems and everything you tell them will be treated confidentially. You could write down any questions or concerns you may have and give these to the healthcare professional you are seeing.

Can impulsive behaviour be controlled?

Yes it can. Treatment can involve reducing the dose of the medicine or safely switching to another medication that is also used for the treatment of RLS.

Do not stop or change your medication without first speaking to your doctor or pharmacist. Any changes should be made gradually. Changes to your medicine should always be carried out and reviewed by a specialist because of the risk of side effects and withdrawal symptoms such as depression, anxiety or pain.

Depression may increase the development of impulsive behaviour. Treating mood problems may also help control impulsive behaviour. Speak to your doctor about having a general mental health assessment if you believe this may be an issue.

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.

For further information on side effects, please see the manufacturer's leaflet that comes with the medicine. If any of the side effects persist or become a problem, contact your GP, consultant or pharmacist

Useful sources of information

RLS-UK Supporting people with Restless Legs Syndrome – <http://www.rls-uk.org/>

You might find this charity's website useful for connecting with patients who suffer from the same condition as you, but any new information found should not alter your current treatment regimen and you should discuss any new advice with the doctor caring for your condition.

Contact us

If you have any questions or concerns about your sleep disorder please contact the Sleep Disorder Centre on 020 7188 3430 (9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Useful contact information

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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