

Hallucinations and delusions in Parkinson's

Some people with Parkinson's may experience hallucinations or delusions. They usually happen as a side effect of your Parkinson's medication. But in some cases they may be a symptom of your Parkinson's, or another condition, such as dementia.

This information looks at what hallucinations and delusions are, the different types you might experience and how they can be treated. It also explains how you can manage them.

What are hallucinations?

Hallucinations can affect all of your senses. A hallucination is when you see, hear, feel, smell or even taste something that isn't actually real.

There are different types of hallucinations:

Auditory hallucinations – hearing things

You may hear sounds or voices that other people cannot hear, such as music or people talking. Or, you could be convinced you've heard a familiar sound, such as a door opening or a doorbell ringing.

Tactile hallucinations – sensing things

This is when you think that someone or something is touching you or the space around you, even when nobody is.

Hallucinating smells and tastes

You may be able to smell something, such as smoke, or taste something you haven't eaten.

Visual hallucinations – seeing things

You may have hallucinations where you see people, particularly relatives, animals or even insects, that aren't there.

If you've had a visual hallucination, it is likely that you will be able to describe what you have seen in detail. The images may go away quickly or be remembered for a long time.

Illusions

These are a different type of hallucination. If you experience an illusion, you will see real things in a different way from how they look in real life. For example, patterns on carpets and wallpapers may seem like they are moving, or a coat hanging on a door may look like a person.

How can hallucinations affect me?

Hallucinations can be quite frightening, especially when you don't realise that the things you see, hear or feel aren't actually real. Some people will be aware that they are hallucinating, and some won't be.

How hallucinations affect you will depend on how bad your experiences are and how other people around you respond.

Hallucinations may also affect you more if you have dementia or memory problems.

Some people find their own ways of dealing with their hallucinations, but if you are finding it hard to cope, there are things that can be done to help (see the section *What can you do to manage hallucinations and delusions*).

Older people are more likely to experience urinary or chest infections, which can cause hallucinations. If you are an older person with Parkinson's it is important to be aware of this and get medical advice as soon as possible.

Delusions

What are delusions?

Delusions are strongly held thoughts or beliefs that aren't based on evidence. This can be one of the most difficult experiences to come to terms with, especially if you have delusions about your carer or someone close to you.

Delusions can include:

Paranoia You may believe you're the victim of a conspiracy, or that someone is trying to hurt or harm you.

Jealousy You may feel jealous of someone you love or a close friend.

Extravagance You may think you've got special powers. This could make you act in an unusual or dangerous way.

How can delusions affect me?

When delusions are less serious, you may know what is happening and you can be helped to understand and make sense of these beliefs.

But sometimes delusions can make people suspicious and mistrusting. This can cause problems – for example, family members may be accused of doing something they haven't done.

If you have severe delusions, you may no longer be able to tell whether things are real or not. This can make you feel very anxious or irritable.

Some people have paranoid delusions where they think someone is planning to cause them harm. For example, you may believe that your carer is trying to give you too much medication or the wrong type of medication. This could have a big effect on how your drug regime is followed and leave you not wanting to take medication.

People who experience delusions may not realise their beliefs aren't actually real. This can make them frightened or upset. So it is important that your family and carers know what medication you take so they can spot any signs as soon as they start.

Some people with Parkinson's experience a mixture of hallucinations and delusions. This could lead to you feeling confused and could affect your daily life.

Will I experience hallucinations and delusions?

Hallucinations and delusions can affect both younger and older people in the earlier stages of the condition, but are more common in people who've had Parkinson's for a long time.

Why do some people with Parkinson's experience hallucinations and delusions?

There are many reasons why someone with Parkinson's may experience hallucinations and delusions.

Parkinson's medication

Hallucinations and delusions may be a side effect of Parkinson's medication. But not everyone who takes Parkinson's drugs will experience them. It depends on the exact type of medication, the dose and the person taking them. Sometimes, the higher the dose of medication, the more chance there is of experiencing hallucinations.

In particular some people with Parkinson's can experience hallucinations or delusions when they have an 'off' period. This happens when your medication wears off before your next dose.

If you think your hallucinations are linked to your Parkinson's medication, speak to your GP, specialist or Parkinson's nurse as soon as possible about adjusting your dose or changing medication. Your pharmacist will also be able to help you.

Memory problems and dementia

Research shows that hallucinations and delusions often happen when someone with Parkinson's also has problems with memory, thinking problems or dementia.

If you experience hallucinations at an early stage of Parkinson's, it could be a sign of another medical condition, such as dementia with Lewy bodies.

Find out more: [see our information on mild memory problems and dementia with Lewy bodies.](#)

Eye problems

Eye problems are more common for people with Parkinson's than those without the condition. Issues with eyesight can often be linked to hallucinations and delusions so speak to your specialist or Parkinson's nurse to find out about the best way to manage any eye problems.

Bad lighting can also be a cause of hallucinations and delusions so make sure you can see clearly in your home to rule out this issue.

Find out more: [see our information on eyes and Parkinson's.](#)

Depression, sleep problems or very severe Parkinson's movement symptoms have also been linked to hallucinations and delusions.

What can you do to manage hallucinations and delusions?

If you experience hallucinations or delusions, you should see your specialist or Parkinson's nurse as soon as you can to find out how to reduce them and the distress they often cause.

You should also do this if you've had hallucinations or delusions before, and they are getting worse.

Simple blood or urine tests may help to make sure that another problem, such as a fever resulting from a chest or bladder infection, is not causing your hallucinations or delusions.

Managing your symptoms at home

There are also some simple steps you can take to manage and reduce your hallucinations or delusions, such as the following:

- Try to recognise that hallucinations are a common symptom of Parkinson's, and that they can be managed. Try challenging and reframing any negative thoughts in a helpful way. For example, replacing thoughts like 'I'm going mad' with 'this is normal, and I'm going to be okay'.
- Check the time your symptoms begin to occur, and consider moving your medication time backwards or forwards slightly, if you find it is impacting on your hallucinations or delusions. For example, if your hallucinations happen when your medication is wearing off, you might want to consider taking it slightly earlier.
- Focus your attention on a stimulating activity, such as reading or watching television, to distract yourself from the hallucination or delusion.
- Don't react to any visions or sounds – instead, block them out and try distracting yourself (see above)
- Try to practise good sleeping habits, as tiredness can bring on or increase hallucinations. Avoid caffeine and other stimulants (eg nicotine and alcohol) too close to bedtime, and engage in a relaxing activity before going to bed (eg reading or listening to music).

Find out more: [see our information on sleep and night-time problems](#)

- Consider adjusting your environment to reduce any triggering sights and objects. For example, improving the lighting to reduce shadows, and removing or covering objects which could cause hallucinations.
- Eating regular, nutritionally balanced meals can help to reduce the symptoms of hallucinations and delusions, as can frequent exercise.

Find out more: see our [information on diet and Parkinson's](#), and [staying active and exercising at home](#).

Talk to your family

It can help them to understand how you are feeling and become more patient so they can help you to manage your hallucinations or delusions. If people around you can understand and support you, this can make you feel less worried.

If you have carers at home, help them to understand the following:

- What happens when you experience hallucinations or delusions?
- When are they most likely to happen?
- What makes them happen less often and less strongly?
- How can your carers or family members make things easier for you?

Ask about medication

Because the hallucinations and delusions may be caused by Parkinson's medication, your GP, specialist or Parkinson's nurse may suggest some changes to your Parkinson's treatment. They will aim to find the right medication for managing both your hallucinations or delusions and your other Parkinson's symptoms.

Your current dose may be reduced, or a certain type of medication may be gradually stopped to help improve these symptoms. If this doesn't work, then your specialist may suggest that you take medication that can stop hallucinations or delusions from happening.

Research shows that experiencing hallucinations or delusions can have a big effect on the quality of life of people with Parkinson's. It can also be very upsetting to carers and can put stress on relationships.

Sometimes carers and family members can find it hard to cope with hallucinations and delusions. So it is very important to get medical treatment for hallucinations and delusions, or to learn ways of dealing with them when they happen.

Tips for family, friends and carers

Coping with hallucinations and delusions can be stressful and tiring for people with Parkinson's and the people who care for them. You can support someone experiencing hallucinations or delusions in these ways:

- If someone you know with Parkinson's is experiencing any of these symptoms, the most important thing is to get medical advice. Remember that if the person with Parkinson's understands there is something wrong, make sure you are clear who you are going to contact and why. This will avoid any extra confusion.
- In general, hallucinations and delusions can be treated. They should improve with the right treatment and medication but this doesn't always work. In this case it is important to get help dealing with any distress from the person's healthcare team.
- Don't rely on someone telling you they are experiencing hallucinations or delusions. They may not realise what they are, or they may not want to tell you. If they seem to be behaving or reacting in a strange way, gently ask them what the matter is. If you are unsure, explain that you are going to contact their GP, specialist or Parkinson's nurse.
- Even if the hallucinations are not upsetting or disturbing, it is still important to tell a member of their medical team if they are a new problem.
- You should also speak to a member of the medical team if the hallucinations or delusions seem to be getting worse. Don't wait for the next appointment.

- If hallucinations or delusions are very severe, telling the person experiencing them that they aren't real may not help. It could lead to conflict and is unlikely to be effective.
- It's important not to argue with the person experiencing the hallucination, or deny what they are seeing is real. You should instead acknowledge their experience and try distracting them from it. Do not engage or join in with their hallucination.
- Anxiety may make hallucinations and delusions worse. Try to find ways to help the person relax such as talking to them calmly or taking them somewhere quiet.
- Some delusions can lead to safety issues, such as someone leaving the house in the middle of the night. In these cases, get advice from their specialist or Parkinson's nurse.
- Sometimes, your loved one may think you're part of the hallucination or delusion. Consider having a pre-agreed 'code' to use to help reorientate and bring them back to the present. This could be an object like your wedding ring or a necklace.
- Managing hallucinations or delusions and giving support can be tiring. So get support for yourself from those around you and remember to recharge your batteries.
- Sometimes it helps to speak to someone about how another person's symptoms are affecting you. This could be your own GP or a counsellor. You can also get support from other local services to help you manage at home.
- Talk to other people affected by Parkinson's who may have had a similar experience and can provide tips and advice. You can speak to others at your local Parkinson's UK group or on our online forum.

Counselling

Counselling can help you and the person experiencing hallucinations and delusions. Many GP surgeries have counsellors attached to their practice or can give information about other local services.

There are also counselling organisations that can give information and details of private counsellors.

The mental health charity Mind has a range of guides, including *Making Sense of Talking Treatments*. This

covers what counselling is, how it can help, what it involves, the types available and how to find a counsellor. There is a small charge for this booklet if you order a printed copy, however you can view and print it online for free.

You can find details of all these organisations in the next section of this information.

More information and support

Local mental health services

Speak to your GP about accessing mental health services in your area. Staff in mental health services usually consist of trained mental health nurses, psychologists and psychiatrists. You can find out more information about local health services on these websites:

- England www.nhs.uk
- Northern Ireland www.online.hscni.net
- Scotland www.nhs24.scot
- Wales www.nhsdirect.wales.nhs.uk

British Association for Counselling and Psychotherapy

01455 883300
bacp@bacp.co.uk
www.bacp.co.uk

British Association for Behavioural and Cognitive Psychotherapies

030 320 0851
babcp@babcp.com
www.babcp.com

Mind

0300 123 3393
Text 86463
info@mind.org.uk
www.mind.org.uk

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

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

Visit parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.

Thank you

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

**Emma Grace, Lead Clinical Pharmacist,
Nottingham University Hospitals Trust**

**Amanda Mobley, Consultant Clinical
Neuropsychologist, Newtown Hospital**

**Chris Street, Chief Pharmacist,
James Paget University Hospital**

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

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 **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and 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.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**



Hallucinations and delusions (PKFS11/2019)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to **Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**, or email **publications@parkinsons.org.uk**. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in I care for someone with Parkinson's
 I have a friend or family member with Parkinson's I'm a professional working with people with Parkinson's
 Other (please specify)

2. Where did you get this information from?

- GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser
 Ordered directly from us Call to the helpline
 Other (please specify)

3. Has it answered all your questions?

- Yes, completely Yes, mostly Not sure Partly Not at all

4. How easy was it to understand?

- Very easy Easy Not sure Quite difficult Very difficult

We're the Parkinson's charity that drives better care, treatments and quality of life.

Together we can bring forward the day when no one fears Parkinson's.

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

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm, Saturday 10am–2pm).
Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see www.ngts.org.uk

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: PKFS11

Last updated August 2019. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.

© Parkinson's UK. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).



5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

It helped a lot It helped a little No change It didn't help It made things worse

6. What is your ethnic background?*

Asian or Asian British Black or Black British Chinese Mixed White British White other
 Other (please specify)

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

I would like a response to my feedback I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name _____

Address _____

Email _____

Telephone _____

How would you prefer us to contact you? Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions