

# Hallucinations and delusions in Parkinson's

**S**ome people with Parkinson's may experience hallucinations or delusions. A hallucination is when you see, hear or feel things that aren't there. Delusions are unusual thoughts, beliefs or worries that aren't based on reality.

**This information looks at what hallucinations and delusions are, the different types you might experience and what can be done to treat them. It also explains how to manage them if they can't be treated.**

## **Why do some people with Parkinson's have hallucinations?**

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

Hallucinations may be a side effect of Parkinson's medication. But not everyone who takes Parkinson's drugs will experience hallucinations. 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.

## **What is a hallucination?**

A hallucination is when you see, hear, feel, smell or even taste something that doesn't exist. Hallucinations can affect all of your senses, not just your sight.

There are different types of hallucination:

### **Visual hallucinations – seeing things**

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

If you have 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. This is the most common type of hallucination that people with Parkinson's experience.

### Auditory hallucinations – hearing things

You may hear sounds or voices that do not really exist, or you could be convinced you've heard a familiar sound, such as a door moving or a doorbell ring.

### Tactile hallucinations – sensing things

This is when you think that someone or something is touching you or around or near you, when it isn't.

### Hallucinating smells and tastes

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

### 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 or hear aren't 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, how other people around you respond, and whether you have other mental health issues. 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 about them (see section What can be done?).

## Delusions

### What are delusions?

While hallucinations are seeing, hearing, feeling or even tasting things that don't exist, delusions are thoughts or beliefs that aren't based on reality. Even though they're irrational, you may be convinced they're true. This can be one of the most difficult symptoms to come to terms with, especially if you have delusions about your carer or someone close to you.

“We've discovered that if mum is constipated, has a cold or another mild illness, her hallucinations get worse. This has helped us to gain more control over her hallucinations. We are lucky, as mum knows that she hallucinates and can talk about what she has seen. We often talk it through when she is 'back in the room'.”

### Eve, whose mum has Parkinson's

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 have jealous feelings. For example, you may think that someone you love is betraying you.

**Extravagance** You may think you have special powers that you do not. 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 overcome your false beliefs. But when delusions make people suspicious and mistrusting, they can cause problems in relationships. With a serious delusion, there is a chance you could accuse your partner or a family member of 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 with Parkinson's experience a mixture of hallucinations and delusions. This could lead to you feeling confused and can have an impact on your day-to-day life.

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. This could have a big effect on how your drug regime is followed and leave you not wanting to take medication.

## What can be done?

If you experience hallucinations or delusions, you should:

### Get medical advice

If you start to experience hallucinations or delusions, or you start reacting to strange things that you see, feel, hear or think, it is important to get advice from your GP, specialist or Parkinson's nurse (if you have one) as soon as you can. You should also do this if you have had hallucinations or delusions before, and they seem to be getting worse.

A Parkinson's nurse is a qualified registered general nurse with specialist experience, knowledge and skills in Parkinson's. They play a vital role in the care of people with Parkinson's. You can read more about them on page 5. See the 'More information and support' section at the end for details of other organisations and professionals who may be able to help you.

### Rule out other causes

If you're experiencing hallucinations, it is important to rule out causes other than Parkinson's, such as poor eyesight or bad lighting. Some other medical problems can cause hallucinations or delusions or make them worse.

**Find out more:** see our information sheet *Eyes and Parkinson's*.

Make sure that you discuss your hallucinations or delusions with your GP, specialist or Parkinson's nurse and your loved ones and carers. 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.

Research shows that hallucinations and delusions often happen when someone with Parkinson's also has problems with memory or thinking, dementia, depression, sleep problems or very severe Parkinson's movement symptoms.

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 sheet, *Mild memory problems and Dementia with Lewy Bodies*.

### Talk to your family, as this can often help them to understand how you are feeling

It can help them to become more patient in helping to manage your hallucinations or delusions. If you have carers at home, help them to understand what happens when you experience hallucinations or delusions, when they are most likely to happen, what makes them go away and how they can make things easier for you. If people around you can understand and support you, this can make you feel less worried.

### Ask about medication

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

Your current dose may be reduced, or a type of medication may be gradually stopped to help improve these symptoms. If this doesn't work, then your specialist may introduce medication that can stop hallucinations 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 can find it hard to cope with these symptoms and then different caring arrangements, such as nursing homes have to be considered. So to try and avoid this from happening it is very important to get medical treatment for hallucinations and delusions, or to learn ways of dealing with them when they happen.

### Try not to worry

Although it may be difficult when the hallucinations or delusions seem so real, reassure yourself that they may be a side effect of Parkinson's medication.

## 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 seek medical advice.
- In general, hallucinations and delusions can be treated. They should improve with the right treatment and medication. You should be aware though, that for some people, this may not provide a solution.
- 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 in doubt, contact your GP, specialist or Parkinson's nurse.
- Even if the hallucinations are not upsetting or disturbing, it is still important to tell a member of the medical team if they are a new symptom.
- 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 your next appointment.
- If hallucinations or delusions are very severe, questioning them or doubting their existence (by telling the person experiencing them that they aren't real) may not help. It could lead to conflict and further distress.
- If you're worried about a loved one, give lots of support and reassurance and spend some time trying to understand what they're experiencing.
- Anxiety may make hallucinations and delusions worse. Try to find ways to help the person relax.
- Some delusions can lead to safety issues, such as someone leaving the house in the middle of the night. In these cases, advice from your specialist is crucial, as is support from other local services to help you manage at home.
- Seek support for yourself. Sometimes it helps to speak to someone independently about how

“My mother had a number of recurring hallucinations, all of which were very real to her. The two most common hallucinations she had involved a crying baby in the room that she needed to look after and a man in the room. The most effective way to manage the hallucinations, which were incredibly real to her, was first of all to let her know that I believed her and secondly that I would, for example, look after the baby.”

### Rachel, whose mum has Parkinson's

another person's hallucinations or delusions are affecting you.

- Managing hallucinations (and the support you may have to give) can be tiring for everyone. Make sure you take some time for yourself to recharge your batteries and use the support of the people you have around you. If you need extra help, speak to a healthcare professional.
- If you're worried or have questions about these symptoms, or even about the Parkinson's medication that you, or a family member, are taking, talk about this with your GP, specialist or Parkinson's nurse. You can also call our helpline on **0808 800 0303**.

### Counselling

If either the carer or the person experiencing the hallucinations or delusions wants to talk with someone about the effects that these symptoms may be having, especially on close relationships, they may want to speak to a counsellor. Many GP surgeries have counsellors attached to their practice or can give information about other local counsellors.

There are also counselling organisations that can give information and details of private counsellors. These include the British Association for Counselling and Psychotherapy and the British Association for Behavioural and Cognitive Psychotherapies.

They could also speak to someone else with Parkinson's or a carer they've met through their Parkinson's UK local group – as they may have been through a similar experience.

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 free. See below for Mind's contact details.

## More information and support

### British Association for Counselling and Psychotherapy

01455 883316

Text 01455 550243

[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

[www.bacp.co.uk](http://www.bacp.co.uk)

### British Association for Behavioural and Cognitive Psychotherapies

0161 705 4304

[www.babcp.com](http://www.babcp.com)

### Mind

0300 123 3393

[www.mind.org.uk](http://www.mind.org.uk)

### 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.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)
- Northern Ireland [www.n-i.nhs.uk](http://www.n-i.nhs.uk)
- Scotland [www.nhs24.co.uk](http://www.nhs24.co.uk)
- Wales [www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.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](http://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](mailto: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.

We 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](http://parkinsons.org.uk/selfmanagement)

Our website [parkinsons.org.uk](http://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](http://parkinsons.org.uk/localtoyou)

Visit [parkinsons.org.uk/forum](http://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:

**Professor David Burn, Professor of Movement Disorder Neurology and Honorary Consultant Neurologist, Newcastle University**

**Professor Marjan Jarhanshahi, Professor of Clinical Neuropsychology, UCL Institute of Neurology**

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](https://parkinsons.org.uk/donate). Thank you.

## Our information

All of our most up-to-date information is available at [parkinsons.org.uk/information-support](https://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/ordering-resources](https://parkinsons.org.uk/ordering-resources) 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](mailto:publications@parkinsons.org.uk)



## Hallucinations and delusions (FS11/2013)

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](mailto: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 2013. We review our information within three years.  
Please check our website for the most up-to-date versions of all our information.

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### 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](http://parkinsons.org.uk/termsandconditions)