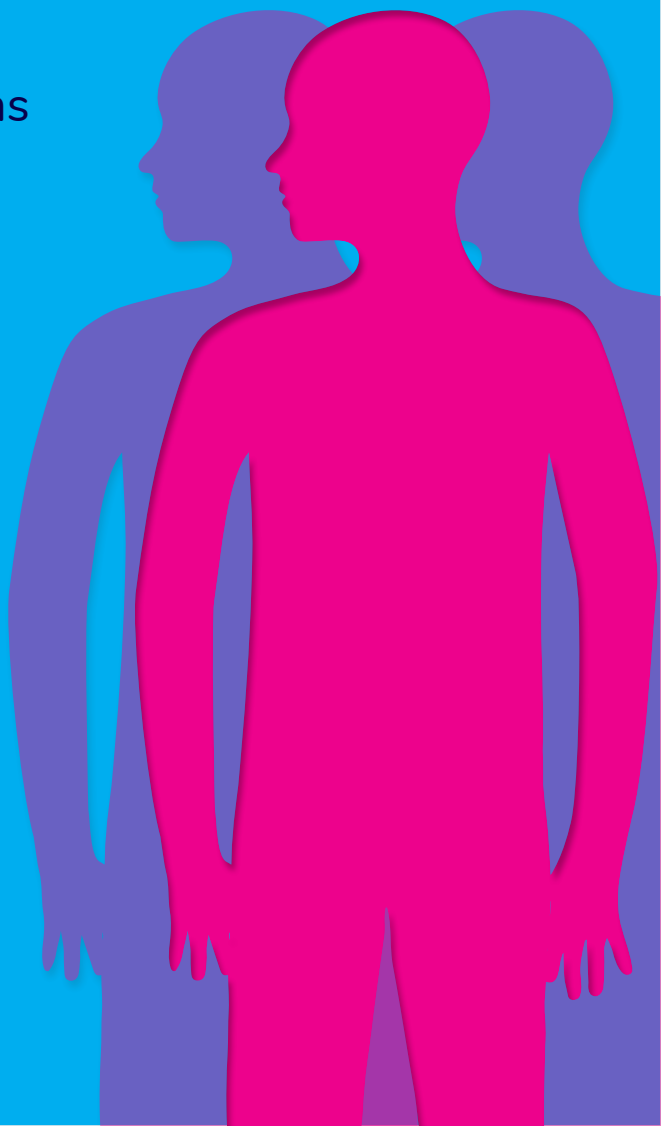


HALLUCINATIONS AND DELUSIONS IN PARKINSON'S

Symptoms

Find out more
about hallucinations
and delusions in
Parkinson's, and
treatments to help
manage them

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.



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. An 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. 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 OK'
- 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 (for example nicotine and alcohol) too close to bedtime, and engage in a relaxing activity before going to bed (for example 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 for 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 8830

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 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

You can read our most up-to-date information at **parkinsons.org.uk**. You can order printed information by calling **0330 124 3250** or visiting **parkinsons.org.uk/orderingresources**

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email **hello@parkinsons.org.uk**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support

through our network of volunteers and local groups. Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **parkinsons.org.uk/forum**

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, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

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 are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

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

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



Registered with
**FUNDRAISING
REGULATOR**

Last updated: August 2019 | Order Code: INFOB0043

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). © Parkinson's UK 06/22 (CS3756)