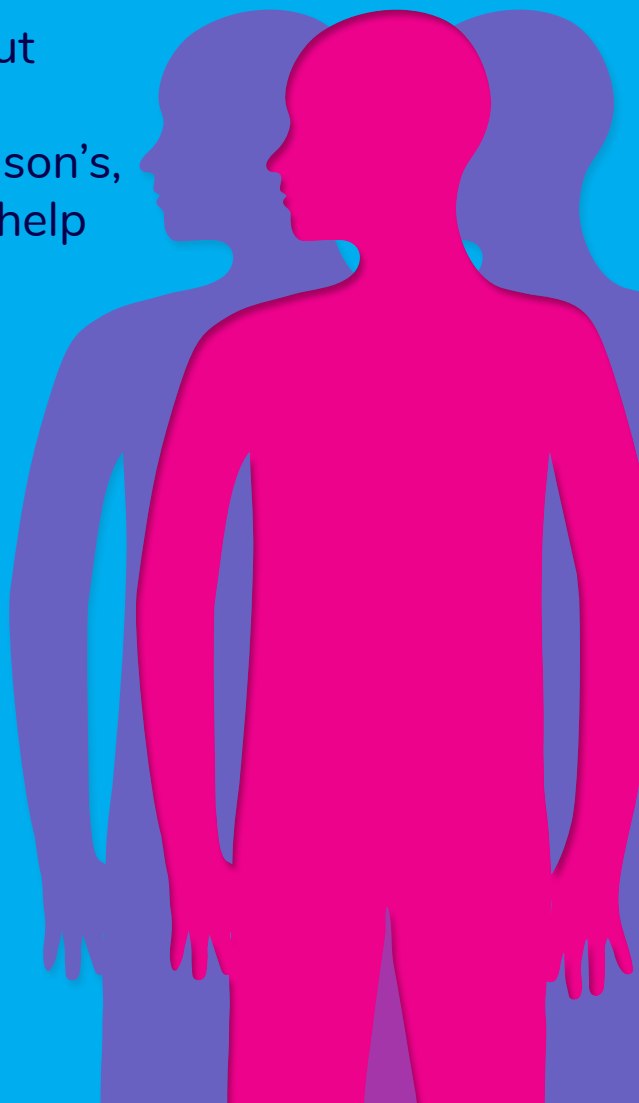


HALLUCINATIONS AND DELUSIONS IN PARKINSON'S

Symptoms

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



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HALLUCINATIONS AND DELUSIONS IN PARKINSON'S

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.

Hallucinations and delusions may be frustrating or frightening for you and the person who cares for you. But they can be treated and managed in different ways.

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, types you might experience and how they can be treated.

What are hallucinations?

A hallucination is when you see, hear, feel, smell or even taste something that isn't actually real.

There are different types of hallucinations that can affect people with Parkinson's.

These include:

Auditory hallucinations – hearing things

You may hear sounds or voices that other people can, 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 – feeling things

This is when you think someone or something is touching you or the space around you, even when nobody is. For example, you might feel like bugs are crawling on your skin.

Presence hallucinations

You may have the feeling that someone or something

is near you, when there's no one there.

Hallucinating smells and tastes

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

Visual hallucinations

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

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

These are the most common types of hallucinations in Parkinson's. They can affect anyone with the condition, but are more common in people who've had it for a long time.

Visual illusions

People with Parkinson's can also experience visual illusions. These are another

type of visual experience which are different from visual hallucinations. They are sometimes referred to as 'minor hallucinations'.

If you experience an illusion, you'll see real things in a different way from how they look in real life. You might see an object as another type of object. For example, a coat hanging on a door might look like a person.

How can hallucinations affect me?

Hallucinations affect everyone differently. They might make you feel anxious or frightened, especially when you don't realise that the things you see, hear or feel aren't actually real. Some people may find them comforting, especially when they first start experiencing hallucinations.

How hallucinations affect you will also depend on how others around you respond.

For example, if a loved one is understanding towards you, it can help you feel less distressed.

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

Some people will be aware that they're hallucinating, and some won't be. If you're not aware of the symptoms, you might not seek treatment for them. Because of this, it's important to know what hallucinations are and what can cause them.

You're more likely to experience hallucinations if you have dementia or memory problems (See the section 'Why do some people with Parkinson's experience hallucinations and delusions?').

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

Speak to your specialist or Parkinson's nurse if these issues are affecting you. You can also contact our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**

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.

It can be especially hard if you have delusions about the person who cares for you, or someone close to you.

Delusions can include:

Paranoia

You may believe that someone is trying to hurt or harm you. Or that several people are secretly planning to harm you (known as a conspiracy).

Jealousy

You may feel jealous of someone you love or a close friend. If you have a partner, you may suspect them of cheating on you. This can cause severe jealousy in some people.

Grandiose beliefs

You may think you've got special powers, or have a relationship with someone famous.

Wrongly identifying people, places and objects

You may not recognise a loved one, or think they're someone else. Or you might think you're in a different place from where you actually are.

How can delusions affect me?

When delusions are less serious, you may know what's happening and you can be helped to understand and make sense of these beliefs. But sometimes delusions can make people suspicious and not trust others. This can cause problems – for example, they may believe a family member has done something they haven't done.

If you have severe delusions, your experience of reality may be quite different to the people around you. This can make you feel very anxious or frustrated.

In some cases, you may worry that the person who cares for you is trying to give you too much medication, or the wrong type. This could affect how you take your Parkinson's medication, or make you want to stop taking your drugs.

People who experience delusions may not realise their beliefs aren't based on reality. This can make them frightened or upset. Because of this, it's important that your family and anyone who cares for you know your medication routine. This can help them spot any signs of delusion as early as possible, if they're linked to your Parkinson's drugs (see the 'Parkinson's medication' section).

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

Speak to your specialist or Parkinson's nurse if these issues are affecting you. You can also contact our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**

Will I experience hallucinations and delusions?

Hallucinations and delusions can affect both younger and older people with Parkinson's. But they're more common in people who've had the condition 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.

This includes:

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 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 specialist or Parkinson's nurse as soon as possible. They can help to adjust your dose or change medication. Your pharmacist will also be able to help you.

A diary can help you keep track of your medication times and when your hallucinations start to happen.

See the 'How can I manage hallucinations and delusions?' section for more information.

Memory problems and dementia

Hallucinations and delusions often happen when someone with Parkinson's also has problems with memory and thinking problems or dementia. Hallucinations can also be a sign of another medical condition, such as dementia with Lewy bodies.

Find out more:
see our information on thinking and memory changes in Parkinson's.

Eye problems

Eye problems are common in people with Parkinson's.

Issues with eyesight can often be linked to hallucinations and visual illusions.

Bad lighting can also cause hallucinations, so make sure you can see clearly in your home to rule out this issue.

Speak to your specialist or Parkinson's nurse to find out about the best way to manage any eye problems.

Find out more:
see our information on eyes and Parkinson's.

Other issues

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

Find out more:
see our information on depression, and sleep and night-time problems in Parkinson's.

What can I 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.

They can advise you on how to manage these symptoms

and the distress they often cause.

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

Getting specialist help

Your specialist will aim to find the right medication for managing your hallucinations or delusions, and your other Parkinson's symptoms.

They'll review your medication and may make changes if your current dose is causing or making your hallucinations worse. If this doesn't help, other treatments will be considered.

Your specialist will also look for things that might be causing your hallucinations, such as infection, or recent medication changes. They may do a simple blood or urine test to work this out.

Managing your symptoms at home

There are also some simple steps you can take to manage and reduce your hallucinations or delusions.

Frame your experience in a positive way:

- 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 more helpful way. For example, replacing thoughts like "I'm going mad" with "This is normal", and "I'm going to be OK".

Check for patterns in your symptoms:

- Check the time your symptoms usually begin, and make your Parkinson's nurse aware. This is particularly important if you find your medication timings are impacting on your symptoms. For example, if your hallucinations happen when your drugs are wearing off. Keeping a diary may help with this.

- Notice if you experience more symptoms when you're doing very little, or when there are lots of noises and distractions around you. Stressful environments can trigger or worsen hallucinations and delusions. Try doing things at a steady pace in a calm environment. This can help reduce these symptoms or anything that might trigger them
- Some people find it helpful not to react to any visions or sounds. Instead, try blocking them out and distracting yourself.
- If you're feeling anxious because of your hallucinations or delusions, you may find it helpful to practise gentle breathing exercises. These can help you relax and reduce feelings of stress. For example, breathing in for four seconds, then breathing out for six seconds. Repeat this three times.

Activities and exercises that can help:

- Focus your attention on an activity to distract yourself from the hallucination or delusion. For example, reading, watching television, drawing, cooking, gardening, or doing a puzzle.
- You could set aside some time to engage with your visions and sounds. Listen to them for a certain amount of time, then write about them, draw them or talk to someone about your experience.
- Mindfulness exercises can be helpful, such as the '5,4,3,2,1' technique. This involves naming five things you can see, four things you can hear, three things you can feel, two things you can smell and one thing you can taste. This technique can help to calm anxious thoughts by encouraging you to focus on the present.

- A ‘good memories’ box can also help with anxiety. This involves creating a scrapbook or shoe box filled with your favourite photos, artwork, poetry, lyrics and other items that help you feel calm and happy. You can include comforting smells, textures and personal items too. You can use the box or scrapbook when you feel stressed or overwhelmed.
- Consider making changes to 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 and nutritious meals can help to reduce the symptoms of hallucinations and delusions. Regular physical activity can also help.

Look at lifestyle changes:

- Try to practise good sleeping habits, as tiredness can bring on or increase hallucinations. Avoid caffeine and other stimulants (such as nicotine and alcohol) too close to bedtime.
- Engage in a relaxing activity before going to bed. For example, reading or listening to music.

Find out more: see our information on diet and Parkinson’s, sleep and night-time problems, and physical activity and exercise.

Talk to your family and loved ones

Speaking to those who are close to you can help them to understand how you’re feeling. It can also help them to help you manage your hallucinations or delusions.

If people around you can understand and support you, this can make you feel less worried.

You could explain:

- what happens when you experience hallucinations or delusions
- when they're most likely to happen
- how they make you feel
- what makes them happen less often and less strongly
- how others can make things easier for you

Hallucinations and delusions can have a serious impact on people with Parkinson's and their quality of life. It can also be very upsetting for people who care for them and can put stress on relationships.

Sometimes family members and people who care for you can find it hard to cope with hallucinations and delusions. So it's very important to get medical treatment for these

issues, or to learn ways of dealing with them.

Cognitive behavioural therapy (CBT)

CBT is a type of talking therapy that can help you change the way you think of hallucinations and delusions and respond to them.

A therapist can work with you to help reduce any anxiety or distress you may be feeling from these issues. They can also teach you ways to deal with hallucinations and delusions in your daily life.

Speak to your GP, specialist or Parkinson's nurse for more advice on CBT, and how to arrange a referral.

Tips for family, friends and those who care for someone with Parkinson's

Coping with hallucinations and delusions can be

stressful and tiring for people with Parkinson's, and those who care for them.

Here are some suggestions about how you can support someone who experiences hallucinations or delusions. This includes tips on looking after yourself.

What you can do for the person you care for:

- The first step is to get medical advice from their specialist or Parkinson's nurse. If the person understands there's something wrong, make sure you're clear about who you're going to contact and why. This will avoid any extra confusion.
- In general, hallucinations and delusions can be treated. They should improve with changes to Parkinson's medication, but this doesn't always work. In this case, it's important to get help dealing with any distress from the person's healthcare team.
- Try not to rely on someone telling you they're experiencing hallucinations or delusions. They may not realise what they're experiencing, or may be worried about telling you. If the person seems to be behaving or reacting in a strange way, gently ask them what the matter is. If you're unsure, explain that you're going to contact their GP, specialist or Parkinson's nurse.
- Tell a member of the person's healthcare team if their hallucinations or delusions are a new problem, or seem to be getting worse. This is important, even if they don't find their symptoms to be upsetting or disturbing. You should do this as soon as possible, rather than waiting for the next appointment.

- It's important not to argue with the person experiencing the hallucination, or tell them what they're seeing isn't real. This could lead to conflict. Instead, acknowledge their experience and be understanding about how they're feeling. Try distracting them from the 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 help them refocus and bring them back to the present. For example, showing them an object like your wedding ring or a necklace.

Looking after yourself:

- Managing hallucinations or delusions and giving support can be tiring. Make sure you get support for yourself from those around you. Finding time to relax is also important.
- 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 with Parkinson's and those who support them. They may have had a similar experience, and can provide tips and advice. You can speak to others on our online forum (**forum.parkinsons.org.uk**) or at your local Parkinson's UK group. Visit **parkinsons.org.uk/localgroups** for details of your local group or contact our helpline on **0808 800 0303**.

Counselling

Counselling can help you and the person experiencing hallucinations and delusions.

It involves a trained therapist listening to you and helping you deal with any emotional difficulties you're having.

You might find this helpful if either of you are experiencing emotional difficulties because of the person's hallucinations or delusions.

Many GP surgeries have NHS counsellors attached to their practice, or can give information about other local services.

If you would prefer to see a counsellor privately, there are organisations that can give you information and details of private counsellors, including the British Association for Counselling and Psychotherapy (BACP). (See the 'More information and support' section).

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.

Other organisations

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 and Mind Cymru

0300 123 3393

info@mind.org.uk

www.mind.org.uk

www.mind.org.uk/about-us/mind-cymru

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

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.

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



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