



Hallucinations and delusions in Parkinson's

Some 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 fact sheet 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 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 can be a side effect of some Parkinson's medications but not everyone who takes Parkinson's medications 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 or smell or even taste something that doesn't exist. Hallucinations can affect any of your senses, not just your sight.

There are different types of hallucinations.

Visual hallucinations – seeing things

You may have hallucinations where you can 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.

Presence and passage misperceptions

Sometimes people with Parkinson's develop unusually strong and recurring perceptions of "presence", that is, the feeling that someone or something is behind or beside them. Another possibility is experiencing the perception of "passage", that someone or something has moved at the edge of their field of vision.

Illusions

These are a different type of faulty perception. 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 they are hallucinating, at least afterwards, 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.

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.

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 abilities or responsibilities that that you do not have. 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 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 medication regime is followed and leave you not wanting to take medication.

WHAT CAN BE DONE?

If you experience hallucinations or delusions, you should:

GET ADVICE

If you start to experience hallucinations or delusions, or you start reacting to strange things that you see, feel hear or think, it's essential you get advice from your doctor, specialist or Parkinson's Community Educator (if you have one) as soon as you can. You should also do this if you have had hallucinations

or delusions for a while and they seem to be getting worse.

RULE OUT OTHER CAUSES

Ruling out other causes can be very helpful, such as eye problems or bad lighting. Other problems can cause hallucinations or delusions or exacerbate them.

Make sure that you discuss your hallucinations or delusions with your doctor, specialist or Community Educator. Simple blood or urine tests may confirm that another common problem is causing your hallucinations or delusions. A fever resulting from a chest or bladder infection for example.

Hallucinations and delusions happen more often for people who have problems with memory or thinking, dementia, depression, sleep problems or very severe Parkinson's movement symptoms. Hallucinations at an early stage of Parkinson's can be a sign of another condition, such as dementia with Lewy bodies.

TALK TO YOUR FAMILY AND CARER

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 your carer can make things easier for you. This can make everyone less worried.

ASK ABOUT MEDICATION

Because the hallucinations and delusions may be being caused by Parkinson's medication, your doctor or specialist 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 and delusions and your other Parkinson's symptoms.

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

Sometimes carers find it so challenging coping with the symptoms that different caring arrangements have to be considered. To try and avoid this from happening it is very important to get medical treatment for hallucinations and delusions sooner rather than later, 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.

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 psychologist, psychotherapist or counsellor.

Again, your doctor's surgery is a good place to start.

Source: Parkinson's UK

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 be 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 doctor, specialist or Parkinson's Community Educator.
- 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 or delusions worse. Try to find ways to help the person relax.
- Some delusions can lead to safety issues, such as leaving the house in the middle of the night. In these cases, advice from your specialist is crucial, as is support from your Parkinson's Community Educator and other local services to help you manage at home.
- Seek support for yourself. Sometimes it helps to speak to someone independently about how 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 your Parkinson's Community Educator or another healthcare professional.

THANK YOU



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