Hallucinations & delusions in Parkinson's

While Parkinson's disease is often thought of in terms of motor symptoms, it can also be characterized by non-motor symptoms, including hallucinations and delusions.

- A **hallucination** means you are experiencing something that others are not – for example seeing, hearing, smelling, tasting or feeling something that isn't there.
- A **delusion** is a false thought, worry or belief that you believe to be true and feels very real, but isn't.

Experiencing hallucinations and/or delusions as a result of Parkinson's is referred to as Parkinson's disease psychosis (PDP).

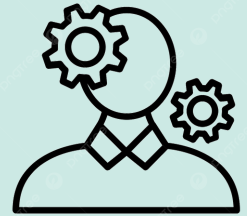
Approximately 50% of people living with Parkinson's will experience some form of hallucinations or delusions during their Parkinson's journey[1]. Hallucinations and delusions can happen at any stage of Parkinson's but usually happen in later stages of the disease. When they happen earlier in Parkinson's, it is usually related to starting certain medication classes or taking higher doses of these medications. However, they can also occur at any stage of Parkinson's due to changes in the brain.

It can be hard to talk about these symptoms and people can feel shame or embarrassment when they occur. You are not alone. The first step towards addressing PDP is understanding and accepting that it is a common problem for people living with Parkinson's and is considered a non-motor symptom, just like constipation, mood or sleep changes.

If you have new or worsening hallucinations or delusions, report them to your care team as soon as you can. They can keep track of these symptoms over time and advise how to manage them. The earlier you can address PDP with your care team, the better you can manage it and improve your quality of life.

Hallucinations

Hallucinations are seeing, hearing, smelling, tasting or feeling something that isn't there. Visual hallucinations (i.e., seeing) are the most common form of hallucination in Parkinson's. Early on, you may notice a shadowy shape or figure out of the corner of your eye or have the sense that someone is standing behind you. For some people everyday objects can resemble something else, for example a curtain may look like a person or a spot of dirt on the floor may look like an insect. That's called an illusion or minor hallucination[2]. Others may experience clear, fully formed hallucinations of things that are not there like people or animals. These hallucinations look very real but no one else is able to see them. This may not bother you at all, for example seeing a friendly cat or dog in your kitchen. Other times hallucinations can cause worry and stress, for example seeing a group of strangers in your home.



Delusions

Delusions are false thoughts, worries or beliefs that are not based on reality or fact. They are not as common in Parkinson's as hallucinations, but they still occur. Some types of delusional thoughts include: the belief that someone is stealing from you, other people are living in your house, your partner is cheating on you or someone close to you has been replaced by another person. These thoughts and beliefs can be very upsetting to the person experiencing them and for care partners. It's important for you to share these thoughts and beliefs with your care team.

For care partners, it is not helpful to try and convince the person of the truth or change their mind. It is best to listen, remain supportive and validate the underlying emotion with both delusions and hallucinations.

Involving your care team

The most important thing when it comes to PDP is to let your care providers and partners know as soon as you notice changes in your vision, hearing, thinking, and/or behaviour. The earlier you can address PDP with your care team, the better you can manage it and improve your quality of life.

Once you bring up your concerns to your care provider, they will typically do a clinical evaluation, review your medications and dosage, assess your lifestyle, and determine your symptoms' severity. This will help your care provider determine if your symptoms are caused by changes in the brain associated with Parkinson's or something else. For example, if they are a side effect of medication or if they are triggered by an acute medical condition called delirium. Delirium is a sudden change in thinking or new confusion that is caused by a change in your health. For some, delirium may be caused by a big medical event like a recent surgery or infection, but it can also be caused by smaller changes like dehydration or severe constipation. If visual hallucinations only happen at night, it's important to distinguish these from very vivid dreams, which are also common in Parkinson's.

Treating hallucinations and delusions

If the hallucinations and delusions are not caused by another medical condition or a new medication, your care provider might look at reducing other medications, including some of your Parkinson's medications. Don't change any medications without talking to your care provider first. Parkinson's medications aren't safe to stop suddenly. This takes careful weaning and monitoring to change or stop Parkinson's medications.

If the hallucinations and delusions continue to get worse and are distressing to you, you may need another medication to help. Some people may interact with the hallucination, for example talking, yelling or even hitting/swinging at the hallucination. This degree of distressing hallucinations or delusions is an urgent reason to reach out to your care team, as an adjustment in your medication and/or another medication may be needed to help.

Your care team will review your Parkinson's medications and may reduce some of the doses if needed, or they may consider an antipsychotic medication. For some people, if they are also experiencing issues with memory and thinking, starting a dementia medication can be helpful.

Strategies for care partners

A **connect and redirect** strategy often helps for both hallucinations and delusions. **Connect** with the underlying emotion – were they feeling worried, angry, sad? It's important to validate the underlying emotional response and then **redirect** to another topic. For example, if someone tells you they saw a stranger in their apartment last night and they seem afraid: "That must have been scary. I'm glad they are gone now." Then, you can move on to another topic: "Why don't we go get some lunch now or go for a walk." If they are actively having a hallucination, for example seeing children in the living room, you could say: "Yes, I think they are leaving soon. Let's go to another room until they're gone."

It's not helpful to try and correct, "There's no one there! That isn't real!", as it feels real to the person experiencing it and trying to correct them can cause more shame and worry.

If you don't know how to respond or what to say – just listen. After they've told you about what they are experiencing, a very simple: "thank you for sharing that with me" is often the most supportive response.

Many people living with Parkinson's will experience some form of hallucinations and delusions during their Parkinson's journey. These symptoms are common and important to talk about with your care team, just like talking about tremors and stiffness. Let your care team know about your experience and they can help – whether it's adjusting medications or checking for any other causes of these symptoms. People with hallucinations and delusions can live well with Parkinson's - talking about it together is the first step.

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References:

1. Forsaa, E. B., Larsen, J. P., Wentzel-Larsen, T., Goetz, C. G., Stebbins, G. T., Aarsland, D., & Alves, G. (2010). A 12-year population-based study of psychosis in Parkinson disease. Archives of Neurology, 67(8), 996-1001.
2. Lenka, A., Pagonabarraga, J., Pal, P. K., Bejr-Kasem, H., & Kulisvesky, J. (2019). Minor hallucinations in Parkinson disease: a subtle symptom with major clinical implications. Neurology, 93(6), 259-266.

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