

Hallucinations and Parkinson's disease

Back in March, more than 500 of you from the PatientsLikeMe Parkinson's disease (PD) community took part in an Open Research Exchange (ORE) questionnaire. You worked with our research partners Dennis Chan and Ruth Wood from the University of Cambridge to understand a symptom called extracampine hallucinations. Everything you shared will help them develop a new tool to better measure this type of hallucination and alert your doctors and care teams to ask about this symptom earlier rather than later. These are your experiences in action and your real-world health data doing good.

About health measures and the extracampine hallucinations

Health measures and patient reported outcomes (PROs) are tools that researchers use to get a better understanding of your experiences with a condition and assess quality of life in ways that matter to you.

PatientsLikeMe's ORE platform gives you—the patient—not only the chance to check an answer box, but also to share your feedback on each question in a researcher's health measure. You can tell our research partners what makes sense, what doesn't and how relevant the overall tool is to your condition. It's all about collaborating with you as partners to create the most effective tools for measuring disease.

What are extracampine hallucinations?

They describe the sense of a presence beside or behind you even when there's nothing or nobody there. So, unlike visual hallucinations, the presence can only be sensed or felt, not seen.

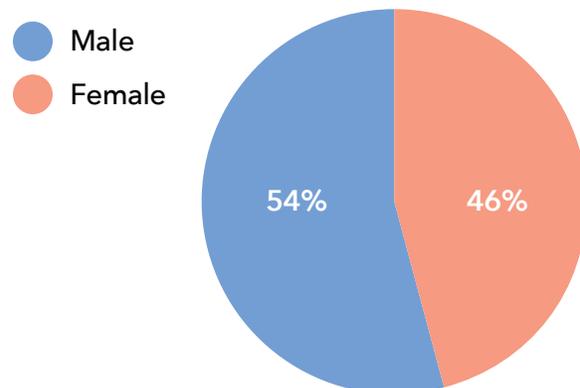


A note from Dennis

"Not much is known right now about extracampine hallucinations or how they relate to other symptoms like trouble thinking or moving. So, the questions we asked were designed to find out how many of you experience them, to learn about how troubling you find these hallucinations and when this symptom occurs: Earlier in your condition progression? Later? Knowing more about extracampine hallucinations will lead to a clearer picture of how PD affects the brain. We can also use this information to advise doctors to ask about these symptoms in their Parkinson's disease clinics. It will also help us to design better tools to measure these symptoms."

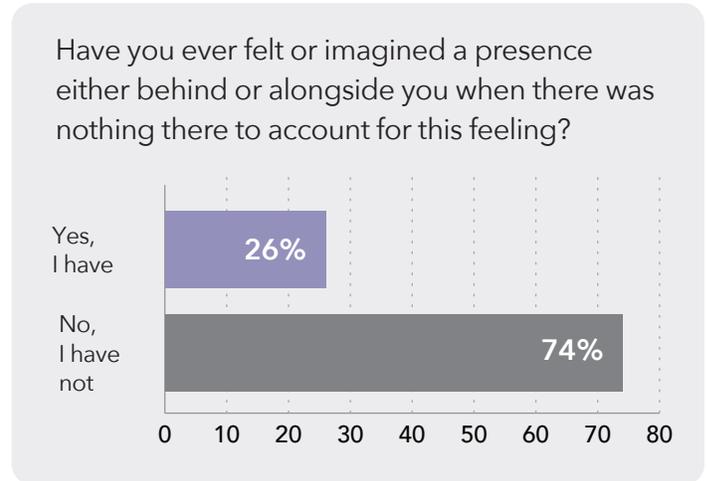
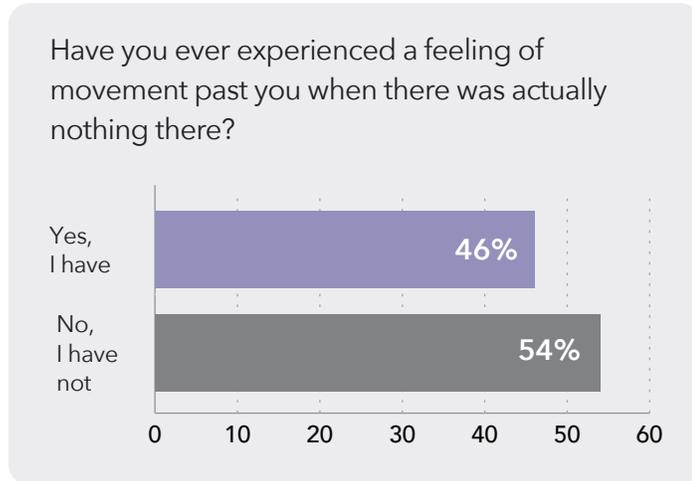
Some of the basics

To get started, Dennis and Ruth asked about some basic information. This was the gender breakdown:

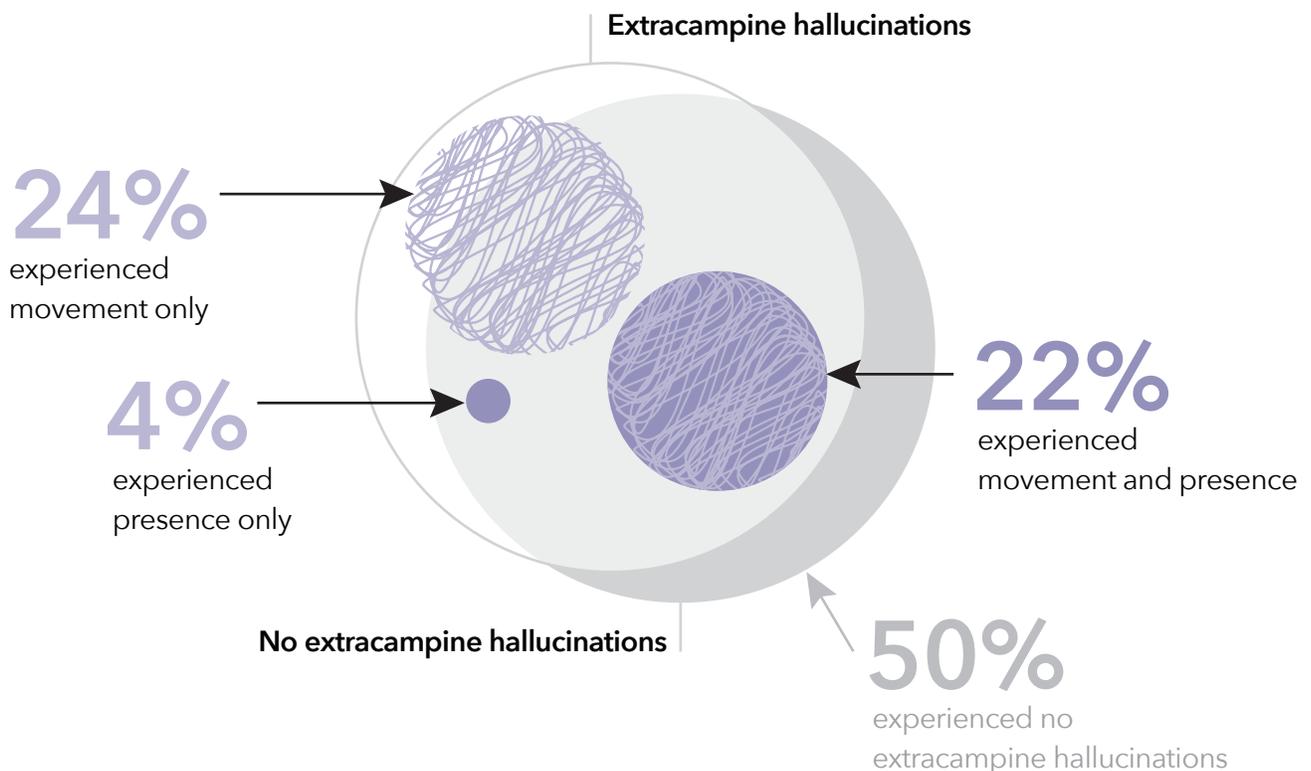


What you shared

Dennis and Ruth asked a couple questions to learn more about your experiences with extracampine hallucinations. Here's what you and the community reported:

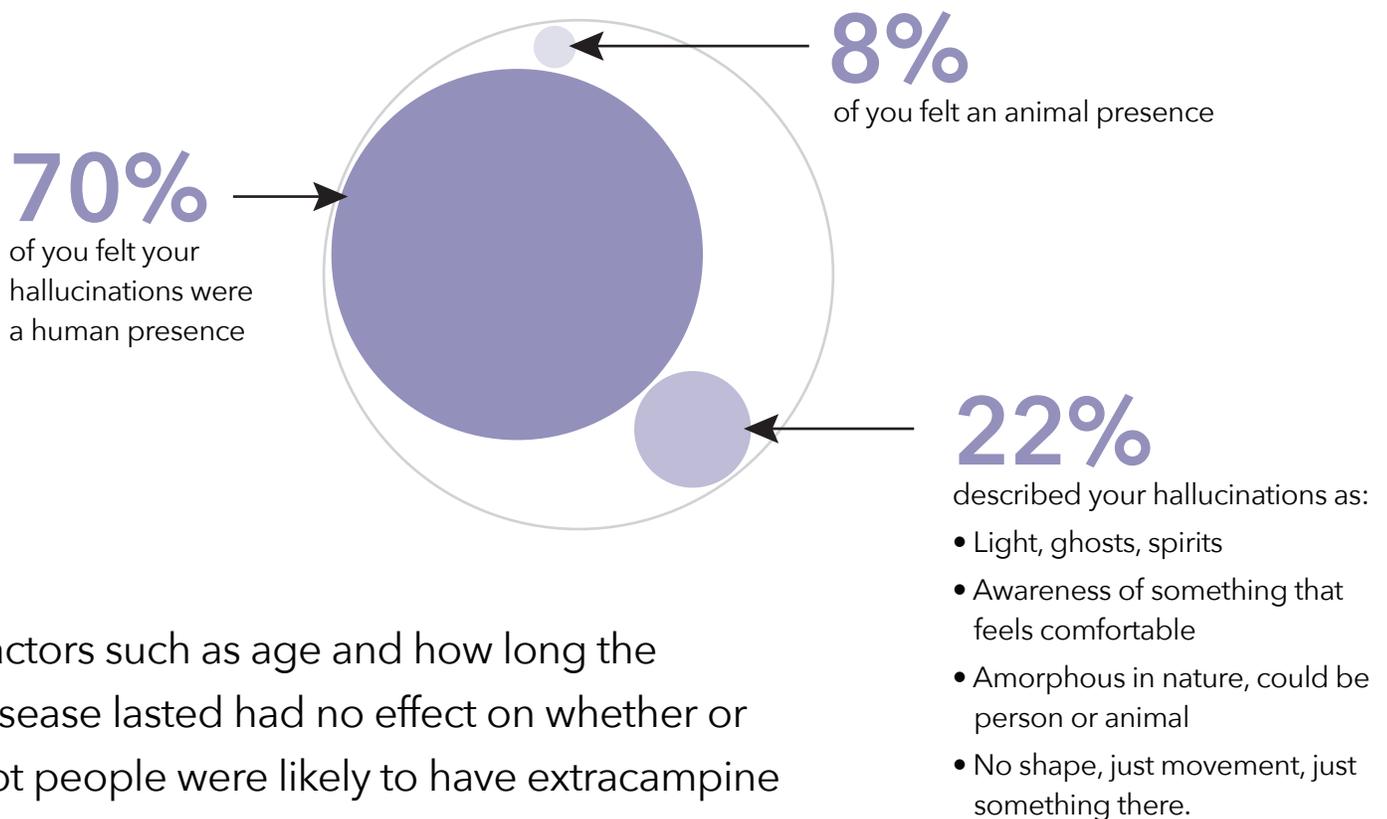


Looking at both questions together, 24% of you reported only a feeling of movement, 4% reported only an imagined presence alongside them, and 22% reported both of these symptoms. This told us that about half of you have experienced an extracampine hallucination. Such a relatively high occurrence suggests that this might be a significant but under-recognized symptom of Parkinson's disease. To confirm, future studies that investigate the prevalence of extracampine hallucinations in the general population should be conducted.



Digging deeper: your experience with extracampine hallucinations

Those of you who've had extracampine hallucinations said that they occur mainly off to the side, rather than right in front of or behind you. And 67% said the hallucinations felt unfamiliar. More than half of you (66%) reported feeling that extracampine hallucinations were neither pleasant nor unpleasant experiences and occurred at all times, night and day. Here's a bit more about how you described the hallucinations you were experiencing:



Factors such as age and how long the disease lasted had no effect on whether or not people were likely to have extracampine hallucinations. But the more severe the PD, the more likely the hallucinations.

More about PatientsLikeMe's Open Research Exchange

With support from the Robert Wood Johnson Foundation, PatientsLikeMe launched the Open Research Exchange (ORE) in 2013 so that researchers, clinicians, academics and patients can collaborate to put patients at the center of the clinical research process. ORE is the hub where we can work together to develop new health outcome measures and increase our collective understanding of disease—faster and better.