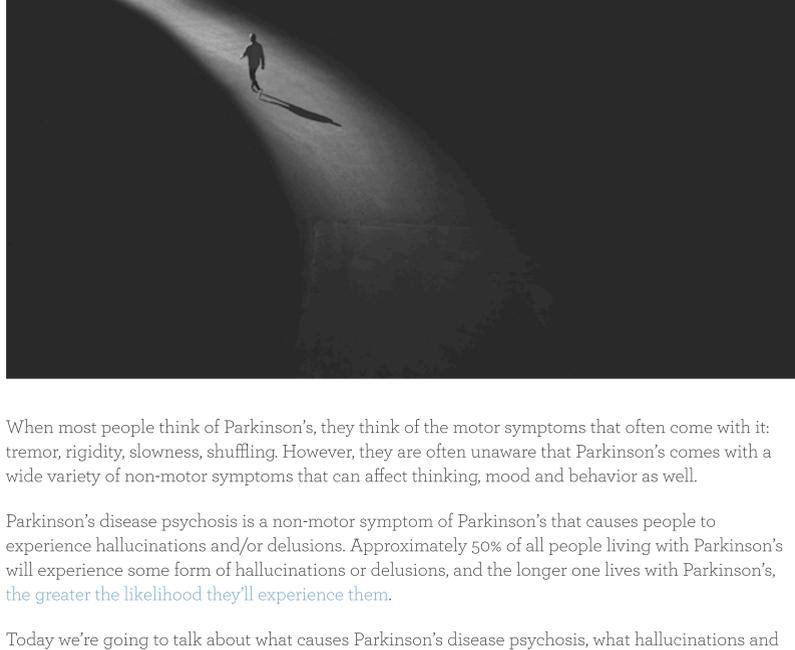


HOW TO BRING LIGHT TO THE DARKER SIDE OF PARKINSON'S: A PRIMER ON HALLUCINATIONS AND DELUSIONS AND HOW TO MANAGE THEM

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When most people think of Parkinson's, they think of the motor symptoms that often come with it: tremor, rigidity, slowness, shuffling. However, they are often unaware that Parkinson's comes with a wide variety of non-motor symptoms that can affect thinking, mood and behavior as well.

Parkinson's disease psychosis is a non-motor symptom of Parkinson's that causes people to experience hallucinations and/or delusions. Approximately 50% of all people living with Parkinson's will experience some form of hallucinations or delusions, and the longer one lives with Parkinson's, [the greater the likelihood they'll experience them.](#)

Today we're going to talk about what causes Parkinson's disease psychosis, what hallucinations and delusions are, what makes some people more likely to experience them than others and what someone with Parkinson's and their care partners can do to manage them.

WHAT CAUSES PARKINSON'S DISEASE PSYCHOSIS?

Parkinson's is a brain disorder associated with a loss of dopamine-producing nerve cells (neurons) deep inside the brain. Dopamine is a neurotransmitter (a chemical substance) that helps regulate the body's movement, and it also allows us to think clearly and regulate our emotions. When you try to replace the dopamine that's been lost in a person with Parkinson's, it can cause the system to get out of whack which can impact thinking, how visual things are processed and more. Parkinson's disease psychosis is therefore typically a side effect of the disease itself or the medications used to manage it.

As a result, it's an ongoing balancing act for Parkinson's doctors to prescribe enough dopamine to control a person with Parkinson's motor symptoms, but not so much that the person experiences hallucinations and/or delusions.

WHAT MAKES SOME PEOPLE WITH PARKINSON'S MORE SUSCEPTIBLE TO PARKINSON'S DISEASE PSYCHOSIS?

Not everyone living with Parkinson's will experience hallucinations and/or delusions, but there are several things that can increase your risk. Here are a few to look out for. Be sure to speak to your doctors and care partners if you notice any changes.

- Decline in memory
- Increased [cognitive impairment](#)
- Increased motor symptoms and disabilities unrelated to Parkinson's
- [History of depression](#)
- Increased sleep disturbances such as [REM Sleep Behavior Disorder](#), sleep apnea, vivid dreaming and sleep interruptions
- Vision problems such as blurry or double vision
- Hearing problems
- Aging (it's common for people to experience vision and hearing problems as they age so the older one gets, the more likely they will be affected by hallucinations)
- Medication changes such as new medication, dosage changes and drug interactions
- Disease progression ([70% of people](#) who have been living with Parkinson's for over 20 years will experience Parkinson's disease psychosis)

WHAT ARE HALLUCINATIONS?

A hallucination is something someone sees, hears, smells, tastes or feels that's not actually there. Essentially they're tricks that the brain plays on the senses. It's estimated that about 50% of people with Parkinson's experience some type of hallucination over the course of having the disease. Most of the time these hallucinations are visual in nature.

For example, one person told us he often sees tiny people along the floorboards in his kitchen. Another one said he sees people who aren't there when he walks into a certain room of his house. One doctor told us about a patient who regularly mistook her laundry piles for a person.

These visions appear clear as day to the person with Parkinson's but cannot be seen by anyone else.

In some cases, the visions may be disturbing and cause emotional distress, but that's not always the case. They may be friendly and not bothersome at all.

When people with Parkinson's first start experiencing hallucinations, they typically experience them with insight. This means that they know what they're seeing isn't real, and they're able to recognize it as a symptom of living with Parkinson's.

On the other hand, when people lose insight, they begin to believe that the hallucinations are real. They may start talking to them, interacting with them and even try to draw their care partner into the scene with them. When their hallucinations reach this stage, they can go on for a very long time and cause hyper-agitation and aggressiveness, which can be very difficult for the care partner to witness and manage.

In addition, whether the hallucinations are distressing or not, just interacting with them can pose a potential risk of harm to them or anyone else in the room.

WHAT ARE DELUSIONS?

Delusions are specific and fixed beliefs that are very real and true to the person experiencing them. They can contradict all semblance of reality and rational thought, but no amount of convincing could change what the person believes is true. Additionally, if you try to convince someone experiencing a delusion that it's not true, they can become suspicious and doubt you which makes an already difficult situation even worse.

Delusions happen much less frequently than hallucinations. Only about 10% of people with Parkinson's experience them, but because they're often ongoing, involuntary and feel very real to the person, they can be much more difficult to manage and treat.

The most common delusions people with Parkinson's experience are:

- The belief that their spouse is being unfaithful
- The belief that their care partner is poisoning them with their medications
- The belief that people are stealing their stuff, or they're going to steal it

Fortunately, many people with Parkinson's have found ways to treat and manage the symptoms of Parkinson's disease psychosis.

WHAT'S THE TREATMENT FOR PARKINSON'S DISEASE PSYCHOSIS?

The single most important thing to do when it comes to Parkinson's disease psychosis is to tell your care providers and partners the minute you notice changes in your vision, hearing, thinking and behavior. The earlier they know what's going on, the sooner they can begin interventions to help you feel better.

Once you bring your concerns up to your doctor, they will typically do a clinical evaluation, review your medications and dosage, assess your lifestyle and determine the severity of your symptoms. Depending upon what they find, they may refer you to counseling or therapy, adjust your medication, change your medication, eliminate medication or do all of the above. If none of those strategies work, they may try antipsychotic drug therapy to see if they can adjust chemical levels in the brain. This can bring with it an entirely different set of problems so it's important to be invested every step along the way and be sure you're well-informed before you move in that direction.

HOW TO CARE FOR SOMEONE WHO EXPERIENCES HALLUCINATIONS

If the person you care for experiences a hallucination, there are a few things you'll want to do in the moment and others you'll want to do when the moment passes.

The most important thing to remember is to never try and talk the person with Parkinson's out of their hallucination. They are actively experiencing it and by trying to talk them out of it, they may either feel like they aren't being heard or that their experience is being diminished.

What matters in the moment is their safety and your reassurance that they're going to be okay. You might calmly say, "I understand that you're seeing X. I'm not having that experience, and I just want you to know that everything is going to be okay, there's nothing dangerous happening here and you're safe."

Other strategies [Dr. Joanne Hamilton](#), PhD, ABPP-CN of Advanced Neurobehavioral Health of Southern California, shared with us are to:

1. Turn on all of the lights to make the room as bright as possible as hallucinations often happen in low lights
2. Have the person look closely at what they're seeing as that can help reset the brain and make the hallucination end
3. If the person does not have insight, give them a lot of reassurance, provide a distraction, move into a different room or suggest a new activity

Here are a few actions you can take once the hallucination has passed:

- Talk to the person about it (most of the time, even if the person does not have insight, they will remember it when it's over)
- Tell their doctor and offer as much detail about the episode you can remember such as time of day, location and anything else like how tired or hungry/full they were that may have had an impact on the situation
- Be sure to keep light switches in convenient locations. Since waking up and going to bed are the most prevalent times for people with Parkinson's to have hallucinations, turn lights on fast and make sure they're bright
- Eliminate/reduce shadows in the house and be careful of where you place mirrors and reflective surfaces as they can play games with the mind
- Investigate any environmental triggers that could be causing them with more frequency or regularity

HOW TO CARE FOR SOMEONE WHO EXPERIENCES DELUSIONS

If the person you're caring for experiences confusion or delusions, here's what you can do in the moment:

- Stay as calm and patient as you can and remember that this belief has nothing to do with you and only with what is going on in their mind
- Remove any objects in the room that could pose a danger to them or to anyone else
- Clear space so there are no tripping hazards and it's easy for the person to move around
- Do not try to reason with the person or convince them why their belief is false
- Reassure them that everything is going to be okay
- If the person becomes aggressive, minimize your movements and remain calm
- Ask the person to talk to you about what they are feeling and really listen to them so they don't feel threatened
- If you feel like you or they are in danger, call 911

Here are a few actions you can take once the delusion has passed:

- Inform their doctor immediately
- Educate others who may care for the person how to handle the situation if it happens
- If the person is open to it, discuss it with them and ask them to explain what the experience is like for them and if there's anything different you could do next time
- Seek expert advice if you feel like you need support in managing these episodes

BRINGING LIGHT TO DARKER SIDE OF PARKINSON'S

Often the hardest part of Parkinson's disease psychosis is the fear of the unknown. As a person with Parkinson's, you may worry about having hallucinations and/or delusions and not being able to do anything about it. As a care partner, you may worry that you won't be able to help your person with Parkinson's feel safe if something does happen.

The good news is you now have information on what Parkinson's disease psychosis is; the risk factors to look out for; biological and environmental triggers that can bring them on; and how to manage them if they show up.

But what about the emotional toll these types of symptoms can place on you over the long-term as the person with Parkinson's or as a care partner?

The diagnosis of a chronic illness in and of itself requires a lot of adjustments. When you add something like Parkinson's disease psychosis into the mix, it's important that you also add another level of self-care to your everyday life.

SELF-CARE FOR THE PERSON WITH PARKINSON'S

- Join a Parkinson's support group if you don't already belong to one. Talk about your experiences, ask for help if you need it and share what's worked and not worked for you.
- Offer to have coffee with someone you know has been newly diagnosed and offer them support and encouragement. (There's nothing more effective for getting out of our own lives than to find someone else to help.)
- Make time to exercise and [get out in nature every day.](#)
- Communicate frequently with your doctors and discuss the possibility of tweaking your medications if your symptoms become worse.
- Rest when you need it.
- Plan a day trip or a weekend and get away from your normal surroundings. (Just make sure you have someone to go with you.)
- Take control where you can and keep authoring your own story.
- Practice [meditation](#) or [yoga](#) or [Tai Chi](#) to relax and calm your mind.
- Start a new project that you're excited to work on every day.
- Communicate with your care partners and let them know how they can best help you.

SELF-CARE FOR THE CARE PARTNER

- Join a Parkinson's care partner support group if you don't already belong to one. Talk about your experiences and ask for help if you need it.
- Allow others to help you care for the person with Parkinson's. Take breaks, get outside and breathe in the fresh air. Connect with the person you are aside from being a care partner.
- Do activities you love and that help you keep your mind off your role as a care partner.
- Get a treatment you love such as a massage or reiki or go to a yoga class, run or play tennis. Whatever it is, do something that brings you joy every day.
- Seek therapy or counseling if you want extra support.
- Identify the people in your life you can trust and share your experiences with them. You don't have to take all of this on your own.
- Be open to what may be the next steps for you and your person with Parkinson's... even if it's not what you imagined. One of the most common reasons for nursing home placement for people with Parkinson's is non-remitting psychosis. If it gets too much for you to manage it on your own, consider potential arrangements that would be best for everyone.
- Keep an open line of communication to your person with Parkinson's care team and don't be afraid to ask for information, help or resources

WHAT'S NEXT?

If you or a loved one are living with Parkinson's disease psychosis, please work closely with your movement disorder specialist to assess your unique situation and create a treatment plan that's right for you. No two people experience Parkinson's disease psychosis in the same way so it's critical to understand and evaluate all of your potential options. Throughout the process, be sure to make note of how you feel, how you behave and how medications or therapies are impacting you on a regular basis so your doctors and care partners can keep an up-to-date record of your experience.

We'd like to thank [Dr. Mark Mapstone](#), [Dr. Joanne Hamilton](#), [Dr. Daniel Weintraub](#) and several people with Parkinson's and their care partners for their expert guidance during the writing of this post.