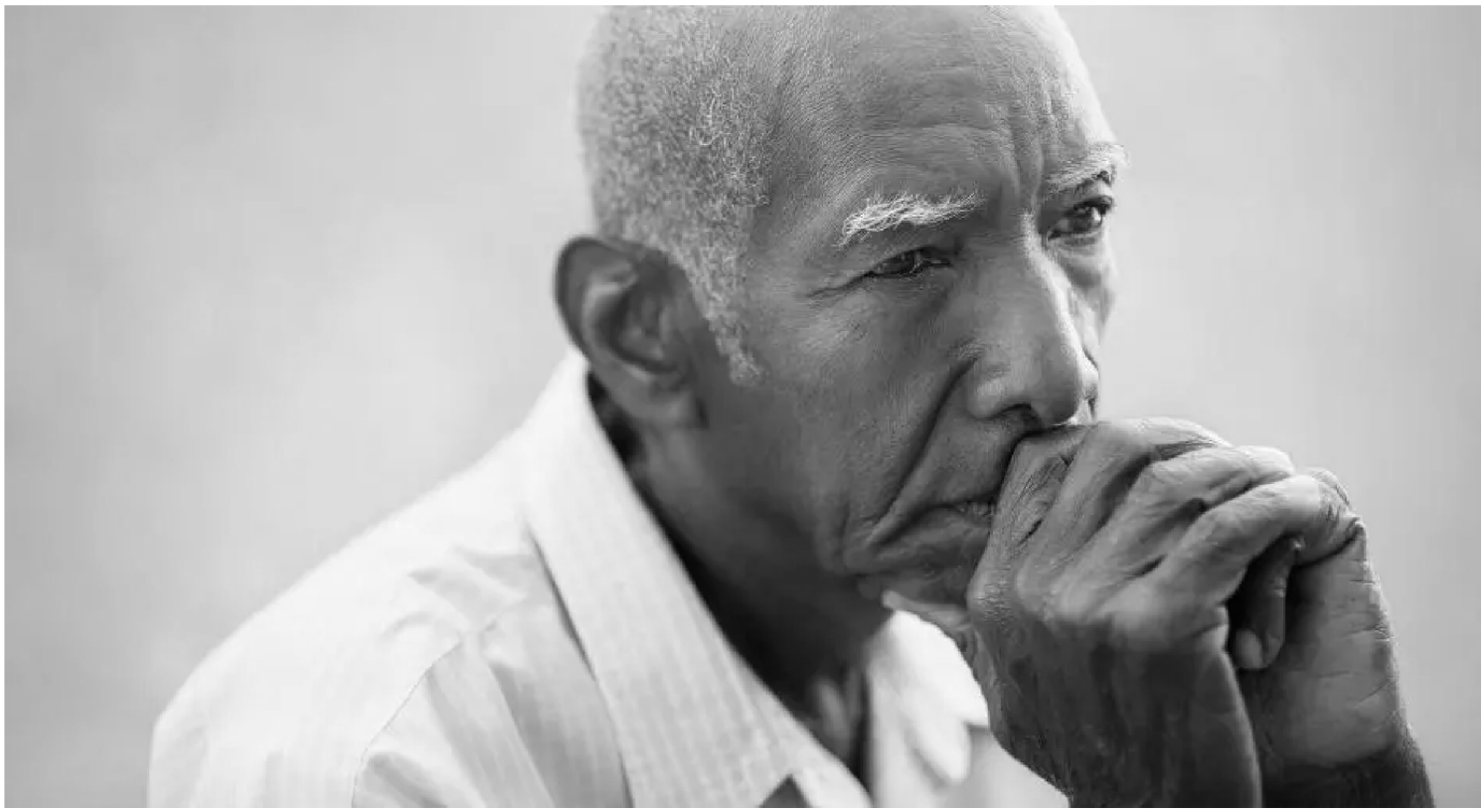
Hallucinations/Delusions



Psychosis can be a frightening word that many people simply don't understand. But what does it really mean? In Parkinson's disease (PD), what your doctor calls psychosis usually starts with mild symptoms, but these can have a big impact on quality of life. Healthcare providers usually refer to these symptoms as "Parkinson's disease associated psychosis." Psychosis can vary from severe confusion (disordered thinking) to seeing things that aren't there (hallucinations) to believing things that are not true (delusions).

It is important to report any hallucinations or delusions to your medical team, even if they are not bothersome

not bothersome.

How common is Parkinson's disease psychosis (PDP)?

Between 20-40% of people with Parkinson's report the experience of hallucinations or delusions.

When followed as the disease progresses over the years, this number increases. The increase does not mean that the hallucinations are persistent across the majority of people with PD. However, it is important to note that these statistics sometimes include "delirium," in which the symptoms are temporary due to medication that needs to be adjusted or infection that needs to be treated, and "isolated minor symptoms" or "minor hallucinations," including illusions, where instead of seeing things that are not there (hallucinations), people misinterpret things that are really there.

These are the most common types of psychosis in people with PD, with different studies placing the occurrence between 25-70% of people with Parkinson's. Typically, if the person with PD only has these minor hallucinations, their doctor will not prescribe an antipsychotic medication, though more significant psychosis that requires medication may develop over time. In one study, 10% of those with minor hallucinations had their symptoms resolved within a few years, while 52% saw their symptoms remain the same and 38% saw their psychosis symptoms get worse.

We recommend that people with Parkinson's not use a single percentage to represent the prevalence of hallucinations and PDP. Parkinson's is a complex disease and as it progresses the percentages and risk of symptoms will change.

What are hallucinations?

Hallucinations are when someone sees, hears or feels something that is not actually there. They are best described as deceptions or tricks played by the brain that involve the body's senses. Hallucinations are not dreams or nightmares. They happen when the person is awake and can occur at any time of day or night.

Types of Hallucinations

- **Visual:** Hallucinations in people with PD are usually visual. Common hallucinations include seeing animals or people, such as a furry creature running by or a deceased loved one sitting in the room.
- **Auditory:** Hearing voices or sounds that are not real is less common but is reported by a small percentage of people with PD.
- **Olfactory:** Smelling an odor that is not related to an actual source is rare in PD.
- **Tactile:** Feeling something imaginary, like bugs crawling on your skin, is rare in PD.
- **Gustatory:** Sensing a bitter or abnormal taste in your mouth that has no source is rare in PD.

More About Hallucinations

- Hallucinations are most often a side effect of medication and are not necessarily a sign of a decline in cognitive abilities. Most hallucinations experienced by people with PD are fleeting and non-threatening. However, in some cases hallucinations may become threatening or bothersome.
- Although hallucinations can affect anyone taking medication to manage PD symptoms, they are more common in people who have problems with thinking or memory, or when under medical stress.
- Visual hallucinations are more likely to occur in low light or low visibility situations. To reduce risk, increase lighting in particularly dark areas, such as hallways.
- Hallucinations may occur in the peripheral vision (out of the corner of the eye), in the form of a flash of light, people or small animals such as cats or dogs. Images often disappear when the person looks more closely.
- Sometimes people with PD have presence hallucinations — the feeling that someone is in the room with them or standing behind them.
- Some people are aware that hallucinations are occurring. This is called “retaining insight.” With insight, you might be able to create coping mechanisms. However,

some people find them incredibly real, or may lose insight as the disease progresses.

Tips for Living with Hallucinations

It is important for people with PD to talk about hallucinations with their family and care team — these are manageable and can be troublesome if not treated. Discuss all possible symptoms with your doctor, no matter how minor, rare or bizarre you may think they are.

- Good lighting and stimulating activities in the evening can help keep hallucinations at bay.
- While a hallucination is occurring, care partners can help their loved one by reassuring them that they will be safe and validating their partner's experience. For example, say, "I'll take the cat outside" instead of arguing that there is no cat.

What are illusions?

Illusions are another sensory misperception. Instead of seeing something that isn't there, people with illusions misinterpret real things in the environment. For example, the clothes in the closet may look like a group of people.

Like visual hallucinations, illusions tend to occur in low light or low-visibility situations.

What are delusions?

Delusions are illogical, irrational, dysfunctional views or persistent thoughts that are not based in reality. They are not deliberate and are very real to the person with PD. People with delusions who feel threatened may become argumentative, aggressive, agitated or unsafe.

Types of Delusions

Some examples of delusions and their impact in PD include:

- **Jealousy**
  - **Belief:** Your partner is being unfaithful.
  - **Behavior:** Paranoia, agitation, suspiciousness, aggression
- **Persecutory**
  - **Belief:** You are being attacked, harassed, cheated or conspired against.
  - **Behavior:** Paranoia, suspiciousness, agitation, aggression, defiance, social withdrawal
- **Somatic**
  - **Belief:** Your body functions in an abnormal manner. You develop an unusual obsession with your body or health.
  - **Behavior:** Anxiety, agitation, reports of abnormal or unusual symptoms, extreme concern regarding symptoms, frequent visits with the clinician

More About Delusions

- Delusions are less common in PD than visual hallucinations. They affect about 8% of people with PD.
- Compared to hallucinations, delusions tend to be more complicated, present a greater risk for behavioral disturbances and safety concerns, are typically more difficult to treat and represent a more obvious deterioration or decline in one's condition.
- Delusions can begin as generalized confusion at night. Over time, confusion can develop into clear delusions and behavioral disturbances during the day.
- Paranoia can lead to medication noncompliance — a person refusing to take medications, believing they are poisonous or deadly.

- Delusions can be associated with dementia. As a result, people with delusions are often confused and extremely difficult to manage. In these cases, many caregivers require outside assistance.

All forms of delusions can be seen with PD, although delusions of jealousy and persecution (like paranoia) are most widely reported and represent a greater challenge for treatment. These delusions can lead to aggression, which can pose a serious safety risk to the person with PD, family members and care partners.

What causes hallucinations and delusions?

Medication, dementia and delirium are the three main contributors to the development of psychosis in Parkinson's disease. Determining the cause can be difficult because these conditions can overlap and produce similar symptoms. Once a probable cause is determined, treatment can begin.

Medications

Many PD medications can lead to symptoms of psychosis:

- Classic PD medications like carbidopa-levodopa (Sinemet) and dopamine agonists are designed to increase dopamine levels, improving motor symptoms. However, by boosting the dopamine supply, these medications can inadvertently cause serious emotional and behavioral changes.
- Other medications used to treat PD can also cause these symptoms by lowering levels of acetylcholine, shifting its balance with dopamine. These medications include amantadine and anticholinergics (Artane and Cogentin). In addition to the prescription drugs, anticholinergics are typically the main ingredient in over-the-counter sleep aids and many allergy medications.

Dementia

Dementia is a term used to describe a group of symptoms associated with a decline in memory and thinking. It is commonly associated with Alzheimer's disease, but people with PD can also develop it.

- Hallucinations and delusions can result from the basic chemical and physical changes that occur in the brain, regardless of other factors such as PD medications. This is most commonly seen in cases of PD with dementia.
- If psychosis and dementia occur early in the disease process, doctors may consider a diagnosis of Lewy body Dementia (LBD).

Delirium

Delirium is a **reversible** change in a person's level of attention and concentration.

- Delirium usually develops over a short period of time (hours to days) and resolves following treatment of the underlying condition.
- Signs of delirium include altered consciousness or awareness, disorganized thinking, unusual behavior and hallucinations.
- Because there are so many symptoms, delirium can be confused with other conditions, such as dementia or drug-induced psychosis.
- To diagnose delirium, a person's level of concentration or attention must go through a change.
- People with Parkinson's have a higher risk of delirium when admitted to the hospital, due to the new settings for the procedure or surgery, which may be unrelated to their PD.

Common causes of delirium include:

- Infection, such as urinary tract infection or pneumonia
- Imbalance of sodium, potassium, calcium or other electrolytes

- Stroke
- Heart disease
- Liver disease
- Fever
- Vitamin B12 deficiency
- Head injury
- Sensory changes, such as hearing loss and vision changes

In addition to medical conditions and changes, many commonly used drugs and chemicals can also cause delirium:

- Anticholinergic medications: diphenhydramine hydrochloride (Benadryl®), trihexyphenidyl (Artane®), benztropine (Cogentin®), ranitidine (Zantac®) and oxybutynin (Ditropan®)
- Narcotics containing codeine or morphine
- Antibiotics
- Nonsteroidal anti-inflammatory drugs (NSAIDS) including Aleve®, Motrin® and Advil ®
- Insulin
- Sedatives
- Steroids
- Anti-seizure medications
- Alcohol
- Recreational drugs

MY PD STORY: DIANE S.

"He would tell me about seeing groups of people in the living room, particularly at night. A man he dubbed “Big Boy” slept in our bed and, sometimes, Jay felt he needed to physically confront him, which could be scary."

READ DIANE'S STORY ›

Risk Factors for Psychosis

Not everyone with Parkinson's will develop hallucinations or delusions, but there are several things can increase your risk:

- Dementia or impaired memory
- Depression: Individuals suffering from depression and PD are at a greater risk. In addition, severe depression alone can cause psychosis.
- Sleep disorders, such as vivid dreaming. Individuals commonly report vivid dreaming prior to the onset of psychosis. Other associated sleep disturbances include REM sleep disorder and general insomnia.
- Impaired vision
- Older age
- Advanced or late-stage PD
- Use of PD medications

Treating Psychosis

Treating Parkinson's disease psychosis is a multistep process that begins with talking to your healthcare team. They will follow a series of steps to figure out how best to address your symptoms.

- **Step 1.** The first step is to perform a clinical evaluation of your symptoms considering prior history, disease stage and available support systems. This assessment will help determine if something is medically wrong and you need treatment right away, or if you can keep an eye on the condition and wait.
- **Step 2.** Treatment, when needed, generally begins with adjustment of your PD medications and referral to counseling. If there is nothing medically wrong with you, your doctor may reduce or eliminate medications, often in a specific order, to lessen the symptoms of psychosis. This is a balancing act as dopamine, which is used to steady your motor symptoms, can also, in high levels, increase psychological side effects.
- **Step 3.** If further intervention is needed, your doctor may initiate antipsychotic therapy, using

- **Step 3:** If further intervention is needed, your doctor may initiate antipsychotic therapy, using drugs to rebalance the chemical levels in the brain and reduce episodes of hallucinations, illusions, and delusions

Medications Used for Treating Psychosis

Antipsychotic Medications

Pimavanserin (Nuplazid®) was approved by the U.S. Food and Drug Administration (FDA) in 2016 specifically for the treatment of Parkinson's disease psychosis.

- Unlike other antipsychotics, it does not block dopamine. It is a selective serotonin inverse agonist, meaning it targets serotonin receptors.

Clozapine (Clozaril®) has been studied and proven effective in improving hallucinations and delusions in PD. However, due to a rare, yet serious side effect known as agranulocytosis — a reduction in white blood cells that interferes with the body's ability to fight infection — there is a tendency use this medication only if quetiapine is not tolerated or effective.

- Anyone who takes clozapine is required to get weekly blood tests for the first six months, and every two weeks thereafter, to monitor white blood cell levels.

Quetiapine (Seroquel®) has fewer side effects, but there is limited evidence for its efficacy in people with Parkinson's.

- It is most often prescribed to be taken just before going to bed because it may be mildly sedating.

Many antipsychotic medications can worsen motor symptoms and should not be prescribed for people with PD. Some of these medications, such as haloperidol (Haldol), are commonly prescribed in the hospital setting for patients who are agitated or anxious.

Treating clinicians should be aware that certain antipsychotic medications can make the

condition of the person with PD worse.

How to Talk to Someone with Hallucinations or Delusions

- It is usually not helpful to argue. Avoid trying to reason. Keep calm and be reassuring.
- You can say you do not see what your loved one is seeing, but some people find it more calming to acknowledge what the person is seeing to reduce stress. For example, if the person sees a cat in the room, it may be best to say, "I will take the cat out" rather than argue that there is no cat.

Page reviewed by Dr. Kathryn P Moore, Movement Disorders neurologist at Duke Health, a Parkinson's Foundation Center of Excellence.

Get Your Parkinson's Hospital Safety Kit

The Hospital Safety Kit includes tools and information that will help people with Parkinson's and their families plan for the next hospital stay.

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