

# Psychosis

**A Mind Guide to Parkinson's Disease**





**Psychosis can be a frightening word that many people associate with movies or the news, or 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. This book explains what Parkinson's psychosis is, why people with Parkinson's might experience symptoms of psychosis, and how to treat it and cope with it.**


The information, tips, and stories included here will provide answers, help you organize thoughts and questions for your medical team, and remind you that you are not alone on this Parkinson's journey. Some of the tips in this book are for caregivers of someone experiencing [Parkinson's disease psychosis](#), but people with Parkinson's will also learn a great deal about the condition from those suggestions for dealing with it.

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## CHAPTER ONE

# About Parkinson's Disease

**If you're reading this book, you are probably already familiar with Parkinson's disease, but here are some basics: Parkinson's is a progressive neurodegenerative disorder that affects about one million people in the United States and 10 million people worldwide. It is called a movement disorder because of the tremors, slow movements, stiffness and muscle cramping it can cause. But its symptoms are diverse and usually develop slowly over time.**

Parkinson's disease is not diagnosed with a test or a scan; instead it is diagnosed by your doctor, who asks you questions about your health and medical history and observes your movement. Your doctor may want you to have some test or imaging; some, like an MRI, can help rule out other conditions, while others, like DaTScan, may help confirm a Parkinson's diagnosis if there is uncertainty. The goal of treatment is to help you manage your symptoms. Good symptom management can help you to stay healthy, exercise and keep yourself in the best possible shape. Although at this time there is no way to correct the brain changes that cause Parkinson's, we know that exercise can help you maintain your ability to fight the disease and that staying healthy can reduce setbacks that make PD progress faster. Great care is key to living your best life with Parkinson's.

Lack of dopamine in people with Parkinson's was first described in the 1960s. Dopamine is a neurotransmitter, or chemical messenger, one of several chemicals your brain cells use to send signals to one another. Soon after, dopamine-replacement therapy using levodopa became – and remains – the gold standard treatment. However, we know that the dopamine system is not the only one affected by Parkinson's. The disease process also disrupts other brain networks, including those linked to mood, behavior and thinking (cognition). You might also hear that Parkinson's is linked to a protein in the human brain called alpha-synuclein. Researchers continue to study how cells and brain networks are affected in Parkinson's to improve our understanding of the disease and potential for treatments.

You and your family may have questions or fears about Parkinson's and genetics. While there are several genetic mutations that can increase your risk, for the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible factors involved in – not necessarily causes of – disease development.

## What Does "Psychosis" Mean?

The word "psychosis" has a long history, with roots in Latin and Greek. Across history, the meaning of the word has evolved, but from the 1800s on it has been used as we understand it today: to refer to a break with reality. This break from reality can range from severe confusion (disordered thinking) to seeing things that aren't there (hallucinations) to believing things that are not true (delusions). Psychosis in other conditions, such as schizophrenia, can include many symptoms that are rare in people with Parkinson's.



CHAPTER TWO

# What Is PD Psychosis?

When most people think of Parkinson's, they think of tremors, stiffness or slowness of movement. Many people are unaware that PD can affect thinking, mood and behavior, among other changes. For people with Parkinson's and their caregivers, living with the motor symptoms can be hard, but behavior changes can be even more frustrating and challenging, and these changes can have a huge impact on quality of life. No two people with Parkinson's are the same, and most people do not develop every symptom. This can be particularly frightening if you don't know what is happening, so it is important to be able to recognize the symptoms if they happen to you or a loved one. Healthcare providers usually refer to these symptoms as "Parkinson's disease-associated psychosis."



## How Common is Parkinson's disease Psychosis?

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 patients. 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.

When looking at these statistics, it is important to remember that for a long time, Parkinson's clinicians and researchers did not include minor hallucinations when studying Parkinson's disease psychosis (PDP), but in most studies that is no longer the case. The criteria being used now does not require significant impairment or distress as a result of the psychotic symptoms and means that our estimation of the prevalence of psychosis has increased. Studies using the new criteria exclude delirium and rule out those who have their diagnosis changed from PD to Lewy Body dementia (LBD), but it is likely that some study participants fall into these categories and are included in studies by mistake.

As we study PDP more with this new definition, we will likely see better estimates of how common these symptoms are, and hopefully will develop a better way to distinguish between psychosis that requires antipsychotic medication versus milder psychosis that can be monitored by clinical specialists without a prescription of an antipsychotic medication.

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

It is important to report any hallucinations or delusions to your medical team, even if they are not bothersome. For more information, call the Parkinson's Foundation Helpline 1.800.4PD.INFO (1-800-473-4636)

## Understanding psychosis

Many people are not aware that hallucinations are a possibility in the Parkinson's progression, so the surprise and fear associated with these new symptoms can be magnified.

Not everyone will get Parkinson's disease-associated psychosis. Like other aspects of PD, there is great variability in when and if people develop psychosis. Some people experience symptoms as early as three years after diagnosis; others develop symptoms after as long as 25 years living with Parkinson's; and others never experience psychosis symptoms at all. Awareness and understanding of the cause(s) and symptoms can help with early and appropriate diagnosis and treatment.

Psychosis can be defined in two ways:

- A symptom of a medical condition characterized by a loss of contact with reality; or
- A psychiatric disorder that produces psychotic symptoms.

Parkinson's disease psychosis is generally the former: in the majority of PD cases, psychosis occurs as a side effect of the disease and medications.

Sometimes, in mid- to late-stage Parkinson's, hallucinations, illusions and delusions may appear as neurologists try to find the right combination of medications to reduce the impact of PD motor symptoms. These should not immediately be considered a new psychiatric illness. Instead, talk to your doctor about the potential causes of and treatments for these symptoms in the context of Parkinson's disease. Some questions to think about to prepare for a conversation with your doctor are on page 19.

### NOTE

**Hallucinations and delusions can be caused by medications and by the same brain changes that cause Parkinson's disease itself. (Turn to Chapter 3, "Causes," on page 13 for more information.) It is important to keep your medical team informed about any symptoms, so they can be effectively managed.**

## What Are Hallucinations?

The term “hallucination” describes something you see, hear, smell, taste or feel that is not actually there. Hallucinations are not dreams or nightmares. They happen when you are awake and can occur at any time of day or night.

Hallucinations are best understood as deceptions – tricks the brain plays on the body's five senses. Hallucinations in people with Parkinson's are generally visual. Common hallucinations include seeing people or animals. While the visions appear real to the person experiencing them, they cannot be seen by anyone else. These “visitors” are generally out of place and might cause concern, though they are not always distressing.

Auditory hallucinations – when you hear sounds or voices that aren't real – are less common in people with Parkinson's. Other kinds of hallucinations can be felt (tactile), smelled (olfactory) or tasted (gustatory), but they are even less common in Parkinson's disease-associated psychosis.

When hallucinations first appear in people with Parkinson's, you might recognize that what you are seeing (or hearing, etc.) isn't real. This is called “retaining insight.” Insight allows you to understand that the hallucinations are a symptom of Parkinson's rather than a new reality. You might be able to create coping mechanisms to help you through the experience. Having insight is common in several psychiatric conditions, though it is more common in illusions than in hallucinations. For example:

**Eleanor was sitting with her friend Margaret one morning at her house. She noticed a dog walking around her couch, sniffing the ground. Eleanor asked Margaret when she got the dog. Margaret replied that she didn't own a dog and that there wasn't a dog in the room. Eleanor realized she must be experiencing what her doctor had warned her about – a hallucination. Margaret asked Eleanor if she had been feeling well. Eleanor said that her doctor had just increased her Parkinson's medications and that she had noticed some visual changes recently. She decided to call her doctor that afternoon to inform him of the hallucination.**

Any hallucination, whether or not it is bothersome, should be reported to caregivers and the medical team. If you can discuss or explain what you are going through, it can help you receive prompt and appropriate treatment. It may also reduce conflict with caregivers and family members.

When people lose insight they begin to believe that the hallucinations are real. When this happens, the person with Parkinson's might try to interact with the imaginary people or objects. This may cause behavior changes in the person with Parkinson's, including [agitation](#) or [aggression](#). Hallucinations without insight pose a greater risk of harm to oneself and those around you, even if the hallucinations are not distressing. For example:

**Christopher would see parades of beautiful wooden puppets marching in front of him. He enjoyed watching the parades and would watch them for hours. One day as the parade was passing in front of him, he tried to step over it, not wanting to interfere with the marching puppets. Unfortunately, he lost his balance while trying to avoid stepping on the puppets and fell, breaking his hip in the process. He spoke to his brother, Patrick, about this accident. Patrick told him they should tell the doctor about the hallucinations.**

## What Are Illusions?

Illusions are another sensory misperception. Instead of seeing things that are not there (hallucinations), people with illusions misinterpret real external stimuli. In other words, they see or hear something wrong, such as mistaking hats on a coat rack for heads, or hearing a chant instead of the air conditioner. For example:

**Drew noticed his wife, Nora, speaking in whispered tones and gesticulating to some hanging plants in their home. When he asked with whom she was speaking, Nora replied that she was talking to the green heads. Drew advised Nora that there were no heads, only hanging plants that could not talk back to her. She accepted this willingly and moved on with her day. However, later on she continued speaking to the hanging plants.**

Illusions can also be experienced as a "[sense of presence](#)" – when you have the feeling of a person or animal being nearby when there is no one around – or as "[passage hallucinations](#)" – when an unformed object moves in your peripheral vision.

### TIP

**Illusions and hallucinations are more likely to occur in low light/low visibility situations. To reduce risk, increase lighting, particularly in dark areas such as hallways.**

## What Are Delusions?

Delusions are false, fixed, idiosyncratic beliefs. They are not deliberate, cannot be controlled and are very real to the person with Parkinson's. Delusions are ongoing and can be subtle. They often begin as generalized confusion at night and progress from there.

**You may never experience delusions – fewer than 10% of people with Parkinson's do – but knowing they are a possibility can help in future planning.** In PD-associated psychosis, delusions occur less frequently than hallucinations and are generally more difficult to treat. They can be associated with medications as well as a general deterioration in condition.

There are three general categories of delusions that come up in Parkinson's disease psychosis:

- Jealous (when you believe your significant other is unfaithful)
- Persecutory (when you believe harm is occurring or going to occur)
- Somatic (related to bodily functioning or sensations, or physical appearance)

Paranoia – when you become suspicious – is a common type of delusion. Paranoia often involves accusations of marital infidelity or fear of being poisoned by medications or food.

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### NOTE

**Delusional thoughts are not deliberate. They cannot be controlled, and the person with Parkinson's cannot be talked out of believing them.**

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**CHAPTER THREE**

# Causes

Parkinson's disease-associated psychosis, like Parkinson's disease itself, is caused by chemical changes in the brain. Dopamine is a neurotransmitter that is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain. In people with Parkinson's, the cells that make dopamine can be impaired or die. Without these cells, there is less available dopamine. With lower levels of dopamine, you experience the motor symptoms of PD.

On the other hand, abnormally high levels of dopamine cause hallucinations and delusions. This increase in dopamine is usually related to the medications prescribed to relieve motor symptoms. It can be a challenging balancing act to provide enough dopamine to control the motor symptoms of PD without providing too much dopamine so that the person with Parkinson's begins to have hallucinations and delusions.

**There are three main contributors to the development of Parkinson's disease-associated psychosis:**

**1. MEDICATION** The most common trigger of PD psychosis is medication. The treatment of PD includes drug therapy to regulate dopamine levels in the brain. As you have likely experienced, finding the perfect medication regimen can be a painstaking process, and it requires a delicate balance. The treatment objective is to minimize symptoms and maximize quality of life. However, adjusting neurotransmitter levels changes the chemical balance of the brain, so people with Parkinson's become at-risk for emotional and behavioral changes.

**Different types of medications can lead to these disruptions:**

- 1) Medications that increase the level of available dopamine. This includes dopamine replacement therapies, such as levodopa converted to dopamine in the brain (e.g., Sinemet) and dopamine agonists.
- 2) Medications that reduce the level of the neurotransmitter acetylcholine, e.g., anticholinergics, which are typically the main ingredient in over-the-counter sleep aids and many allergy medications.

**2. DEMENTIA** To many people, one of the most worrisome aspects of aging and neurological disease is the looming risk of cognitive change, when thinking slows, memory fails and it gets harder to make the right decisions. Over time, some people progress from normal cognition to mild cognitive impairment – when thinking changes start to have an impact on your life – and then to dementia. Dementia is not a specific disease; rather, the term describes a group of symptoms associated with a decline in memory and thinking. It is commonly associated with certain medical conditions, such as Alzheimer's disease, but people with Parkinson's can also develop dementia. Parkinson's disease dementia affects attention, recent memory, executive function and visual and spatial relations. It usually develops years after the PD diagnosis.

Having PD dementia does not mean you also have Alzheimer's. Similarly, when psychosis and dementia occur together and present early in the illness (before or within one year of noticing motor symptoms of PD), an alternate diagnosis of Lewy Body dementia should be considered. The brain chemistry is similar to Parkinson's disease dementia, but treatment may be different. A consultation with your doctor will help to determine if you have dementia, and what type of dementia you have.

**TIP**

**For more information on cognitive issues, including dementia, order the book *Cognition: A Mind Guide to Parkinson's* by calling our Helpline at 1-800-4PD-INFO (473-4636) or online at [Parkinson.org/books](http://Parkinson.org/books).**

- 3. DELIRIUM** Delirium is a reversible medical condition that generally comes on and resolves quickly with treatment. It involves a state of altered alertness, disorganized thinking, unusual behavior and/or hallucinations. Because of these widespread symptoms, delirium can be hard to differentiate from other psychiatric conditions. Common causes include infections (e.g., urinary tract infection), heart or liver disease, chemical imbalance and a host of other common maladies. In addition to medical conditions and changes, many commonly used medications and substances can cause delirium (e.g., alcohol, anticholinergics like Benadryl, opiate pain medications, benzodiazepines like Xanax or non-steroidal anti-inflammatory drugs/NSAIDs like aspirin). Something as simple as taking an allergy medication may trigger a change in mental status.

Aging and disease progression may change the way you metabolize medications and alcohol, so things that had no effect on you before might lead to big changes now. Delirium in people with Parkinson's doesn't occur regularly. It can disappear quickly when the underlying medical condition (infection, etc.) is resolved and might never occur again.

**NOTE**

**If the person with Parkinson's is suddenly and unexpectedly confused or disoriented, contact your doctor or go to a local emergency room. Don't panic. The problem can usually be resolved once the medical team identifies and addresses the trigger. Check your Parkinson's Foundation *Aware in Care* kit for contraindicated medications and be sure to have your updated medication list with you. See page 21 for more information on the kit and how to order your own.**



## Risk Factors for Psychosis in People with Parkinson's

Not everyone with Parkinson's will develop hallucinations or delusions, but there are several things that can increase your risk. You and your caregiver(s) should be aware of the risk factors below and report any changes you experience to your medical team.

### Medications

- New medications
- Changes in existing medications (e.g., a change in your Sinemet dose)
- Use of over-the-counter (OTC) medications like Benadryl, aspirin or ibuprofen

### Dementia

People who experience severe decline in memory and thinking are also more likely to develop psychosis.

### Sleep disorder

- [REM behavior disorder](#)
- [Vivid dreaming](#)
- [Sleep apnea](#)
- Sleep interruptions

If you are affected by one or more of the above sleep disturbances, you may be at greater risk for psychosis.

**Vision problems** Parkinson's can cause changes to a person's vision, making it difficult to distinguish objects. Therefore, people with Parkinson's may need more light to see well. Some people experience double and/or blurred vision. These changes may increase your risk for hallucinations or illusions.

**Hearing problems** Like vision problems, hearing impairment should be addressed, as it increases the risk of auditory hallucinations.

**Age** Older people are more likely to be affected by hallucinations and/or delusions due to visual difficulties that occur with normal aging (e.g., blurred vision, loss of peripheral vision and problems with depth perception).

**Disease progression** As Parkinson's advances, motor and non-motor symptoms alike begin to have a greater impact on quality of life. As part of this progression, there is also an increased chance of developing psychosis.

As with many symptoms, some people will experience psychosis and others will not. Being aware of the warning signs and risk factors will help you to be prepared. Visit [Parkinson.org/Library](http://Parkinson.org/Library) for more Tip Sheets like this.



## CHAPTER FOUR

# Treatments

### Who can help manage Parkinson's disease-associated psychosis?

**Neurologist** – Can make adjustments to your Parkinson's disease medications.

**Primary care doctor** – Can treat causes of delirium (e.g., infection).

**Psychiatrist** – Can prescribe additional medications (e.g., an [antipsychotic](#) that is safe for people with PD) if other attempts to control psychosis are unsuccessful.

**Counselor** – Can talk to you and your family about coping strategies.

**Support group** – A safe place to talk to others with similar experiences.

**Caregiver** – Can help you keep track of changing symptoms, medications and behaviors.

**Person with Parkinson's disease** – You can advocate for yourself! Talk to your family, friends, and healthcare team when you notice changes.

## Preparing for a Medical Appointment

At each visit, your medical team will try to assess any changes to your health. Part of the evaluation might include asking about the presence of hallucinations or other strange ideas. If you are experiencing these, you should tell your medical team right away. Don't wait to be asked. Many people do not reveal these experiences to their family or medical team because they are not sure what is going on, or they are embarrassed. However, it is important to be honest with your care team, so they can help manage symptoms and suggest coping strategies for both the person with Parkinson's and the caregiver. Even hallucinations that are not distressing should be shared. All care decisions should be made with as much information as possible.

Everyone – not only people with Parkinson's – should bring a companion with us to important medical appointments. It helps for the primary caregiver, or other caregiver as needed, to be present to be supportive and take notes, but also to ask questions and share information. This is particularly important when the person with Parkinson's is experiencing hallucinations or delusions and may lack insight into the psychoses. Caregivers have likely noticed (and been affected by) changes in a loved one's behavior, so it is essential to report these changes to the medical team, whether or not they ask about it.

### NOTE

Researchers used data from the Parkinson's Foundation's *Parkinson's Outcomes Project*, the largest-ever clinical study of Parkinson's, to look at how the use of antipsychotic medication relates to health-related quality of life in people with PD. They found that, for patients in the study, antipsychotic medications worked. People who were struggling with psychosis reported improvement in their status when they started taking one.

## Getting Ready for Your Appointment

Knowing when the symptoms started, as well as any changes in the health or medications of the person with Parkinson's, can help the care team understand what is happening and develop a plan of action. Be prepared with answers to the following questions:

- **When did you first experience hallucinations/delusions?**
- **Have there been any recent changes to your medication regimen? Have you started taking a new medication, or have there been any changes in dose or timing of the medications you are currently taking?**
- **Have you experienced any recent changes in health (e.g., recent fall with a head injury, urinary symptoms)?**
- **Have you had any changes in your sleep?**

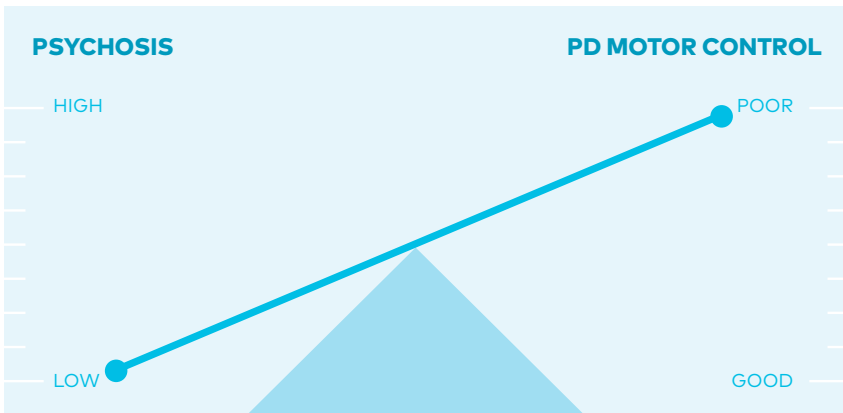
If you look at this list, you'll see that most of these things change if you are admitted to the hospital: you experienced a change in your health, and being in the hospital can change your medication and sleep schedules.

You should make sure someone notifies your Parkinson's specialist if you are hospitalized for any non-PD reasons. It is important for the medical team treating you to understand Parkinson's disease, risk factors and contraindicated medications (the medications that are not safe for you to take). Bring your Parkinson's Foundation *Aware in Care* kit with you for any planned or emergency hospital visit. Turn the page for information on how to order your free kit. Visit [Parkinson.org/Library](http://Parkinson.org/Library) for more Tip Sheets like this.

## Treating Parkinson's Disease Psychosis

Treating Parkinson's disease-associated psychosis is a multi-step 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 drugs to rebalance the chemical levels in the brain and reduce episodes of hallucinations, illusions and delusions.



## Medications for Parkinson's Disease Psychosis

As someone with PD, you understand the importance of medication timing: "on time, every time" is a mantra you know well. You probably also know that there are some medications that are not safe for people with Parkinson's – this includes most of the drugs used to treat psychosis (called "antipsychotics"; e.g., haloperidol, olanzapine, risperidone and ziprasidone). These drugs work by blocking dopamine receptors in the brain, meaning they severely worsen the motor symptoms of Parkinson's and should be avoided.

Thus, medical treatment for hallucinations and delusions can be tricky, so it is important to be familiar with antipsychotic medications. The FDA approved pimavanserin ([Nuplazid](#)) in 2016 as the first drug specifically designed to treat Parkinson's disease-associated psychosis. Other drugs used for psychosis in PD include quetiapine ([Seroquel](#)) and clozapine ([Clozaril](#)). All three are considered safe for people with PD, though they have their limitations.

**Pimavanserin** (Nuplazid) works by targeting a different pathway in your brain: the [serotonin](#) system. It is a [selective serotonin inverse agonist](#). It targets receptors of the neurotransmitter serotonin and does not block dopamine like traditional antipsychotics. This means it can reduce hallucinations without disrupting motor performance.

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**The Parkinson's Foundation *Aware in Care* kit contains information to give to hospital personnel and other medical providers about Parkinson's disease and what medications are safe for people with Parkinson's. Call our Helpline at 1-800-4PD-INFO (473-4636) to request your free *Aware in Care* kit, or order one online at [Parkinson.org/store](#). Review the materials when you receive the kit, so you will be ready to advocate for yourself or your loved one if he or she is hospitalized.**

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**Clozapine** has also been studied and proven to work for Parkinson's disease psychosis. 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 – people on clozapine must have weekly or bi-weekly blood testing, which can be difficult to manage. **Quetiapine** is a similar drug that has fewer side effects, though it has limited evidence for efficacy in people with Parkinson's.

TRADE NAME	GENERIC NAME	STATUS
Nuplazid	Pimavanserin	Approved by the FDA in 2016; shown to be effective, requires less monitoring, does not affect movement symptoms
Seroquel	Quetiapine	Can lead to motor impairment in high doses; studies did not prove efficacy, but it is useful for some patients
Clozaril	Clozapine	Effective, but requires frequent blood tests to monitor for potentially life-threatening side effects

No antipsychotic drug has been found to be completely safe and effective for psychosis in PD. However, many people, in consultation with their doctors, feel that they are willing to accept the risks in order to get the benefits of these drugs. It is important that you talk to your doctor about both sides of the issue.

For your safety, always tell any healthcare provider you see about all the medications and over-the-counter supplements you are taking. Antipsychotics take time to work. Do not stop taking your medication without first consulting your physician.

## CHAPTER FIVE

# Talking about PD and Psychosis

**It is common for people with PD to stop socializing as much as they used to. Sometimes the person with Parkinson's and the primary caregiver isolate themselves, withdrawing gradually from participation in the community and prior social life. This can happen for a variety of reasons including fear of stigma or a lack of confidence to interact with others or perform in social situations. It is normal to feel that way, but if you talk about your Parkinson's, and even psychosis, you'll find out you are not alone.**

Often there are barriers to seeking outside help: the Parkinson's patient's preference that "only s/he can meet my needs"; the caregiver's belief that no one else can adequately provide care or should be saddled with the burden; or the financial pressures of hiring help to facilitate social involvement. Unfortunately, lack of social stimulation is a risk factor for developing symptoms of psychosis and can cause undue strain on the caregiver.

In some cases, the person with Parkinson's is no longer working every day, but the spouse continues to work outside the home. Isolation occurs because it can be hard to get around, or you may feel uncomfortable about attracting attention and having to explain your Parkinson's.



Similarly, some people consider mental illness of any kind embarrassing. The delay in reporting hallucinations and delusions by people with PD and their caregivers is often due to the feeling of disgrace. Again, remember that you are not alone! These symptoms can be a complication of PD: up to 40% of people with Parkinson's will experience them at one time or another. Many of these changes are reversible and can be managed with proper medication after discussion with your healthcare team.

**Frank retired a few years after he was diagnosed with PD, but his wife, Claire, continued to work. Frank would be at home alone all day, except for the occasional visit from the neighbors. He told Claire about their visits, so she asked them when they would be visiting him next. The neighbors replied that they had not actually been visiting Frank! Frank and Claire told his doctor that he was seeing his neighbors when they weren't really there. The doctor explained that Frank was likely experiencing a visual hallucination, which can occur when you don't have a schedule or enough activities to do. Frank was unsure how he would be able to differentiate between the real neighbors and the hallucination neighbors. Claire suggested that Frank place cans of soda next to the neighbors – if Frank noticed the neighbors were drinking the soda, they were real; if not, they were most likely hallucinations. Claire was also able to enroll Frank in an adult day program twice a week, where he receives mental, social and physical stimulation.**

Sharing about Parkinson's, and even your hallucinations and delusions, can make it easier to comfortably socialize. Talking about such a personal subject is easy for some people but can be difficult for others. You do not have to tell everyone – start with a few trusted family members and friends, and get ahead of the questions through education.

First, you must understand the disease yourself. The Parkinson's Foundation offers several options to help you and your family learn about Parkinson's disease, from warning signs and diagnosis through symptoms, treatment and living well. Explore **Parkinson.org** for information on any PD topic, and call our Helpline at 1-800-4PD-INFO (473-4636) with any questions. You may even share this book to help people understand Parkinson's disease-associated psychosis.

**CHAPTER SIX**

# Tips for Caregivers

**Caring for someone who experiences hallucinations and delusions is a difficult job. Much of this guide is directed towards the person with Parkinson's, but it should be noted that the information is valuable to all. This section is directed to caregivers because of the special role you play in caring for someone with PD.**

In some cases behavioral problems add more frustration to the already challenging physical limitations of Parkinson's. In addition, all Parkinson's symptoms can get worse in stressful situations, which makes it even harder for you to help.

Recognizing when someone is experiencing a hallucination or delusion is the first step. The person with Parkinson's may say or do things that are hurtful, and it is important to remember that it is the disease talking, not your loved one. Knowing what to do during a hallucination or delusion is the next step.

## Practical Tips for Caregivers

### **If the person you are caring for experiences hallucinations:**

- 1) Tell their doctor.
- 2) Stay calm and patient.
- 3) Increase lighting at night, which can help reduce shadows and the risk of visual illusions.
- 4) Talk to your loved one about his or her experience.
- 5) If the person has insight, explain that the experience is not real. If the person lacks insight, do not argue or challenge the person by saying "they are not real;" instead, agree and/or distract the person.
- 6) Educate others who frequently spend time with your loved one and allow them to help.

### **If the person you are caring for experiences delusions or confusion:**

- 1) Tell their doctor.
- 2) Stay calm and patient.
- 3) Keep dangerous objects in secure locations.
- 4) Arrange furniture in a way that someone who is confused will not trip and/or fall.
- 5) Do not argue or challenge the person.
- 6) Educate others who frequently spend time with your loved one and allow them to help.

**If your loved one becomes agitated or aggressive:**

- 1) Provide space without crowding.
- 2) Keep dangerous objects in secure locations.
- 3) Talk calmly.
- 4) Provide reassurance: "You are safe."
- 5) Keep your movements to a minimum.
- 6) Ask how the person is feeling and his or her reason for being upset.
- 7) Listen to the responses and comments.
- 8) If your safety is threatened or you are concerned a loved one might harm him/herself, call 911.

**How to prepare for a doctor's appointment:**

Be ready to report any changes in the following:

- 1) Behavior
- 2) Medication
- 3) General health

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## Caring for Someone with PD-Associated Psychosis

- Try to **UNDERSTAND** and acknowledge what the person may be experiencing. This can be challenging for a caregiver but may help you gain a better grasp of the situation.
- Try to actively **LISTEN** while staying calm and patient.
- Try to **TALK** about the experiences. A conversation that is open and non-threatening may reduce the anxiety everyone is feeling.
- Try not to take it personally. It is the disease talking and there is no reasoning you can offer to change that.
- Try to be encouraging and **SUPPORTIVE** rather than argue or debate. Neither challenging nor reinforcing illogical ideas is helpful to the person with Parkinson's or their caregiver.
- Try to find neutral, simple things to talk about.
- Try to show **COMFORT** rather than discredit or tell them they are wrong.
- Try to be **PREPARED**. Know what situations are likely to trigger symptoms of psychosis and what the best remedy is for comforting the person you are caring for.
- Try to **EDUCATE** others who are frequently around. Recognizing these behaviors can relieve fear and make caring for people easier.
- Try to create a safe **ENVIRONMENT** and make necessary adjustments to lighting, objects and distractions.
- Try to keep **SAFETY** first. Having a plan to seek emergency help in case someone is confused, agitated or aggressive will ensure everyone's safety.

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As long as no one is at risk for harm, you can consider acknowledging the experience rather than trying to convince the person that it is not happening. For example, if they see a cat in the room, it may be best to say, "I will take the cat out," rather than argue, "there is no cat." This is not viewed as lying to your loved one; some people use the term "therapeutic fibbing." This approach should be discussed with your doctors.

**Michael's wife, Grace, had Parkinson's disease and experienced some delusions about being at work during the day when she was really at home. She described having to work on filing papers and finish her reports on time. After trying to correct her, Michael realized it didn't do any good, so he played along and wished her luck in finishing the report. Michael spoke to Grace's neurologist about the change at her next appointment. The doctor was able to adjust some medications. After a while, Grace no longer spoke about finishing her reports on time and was able to continue with other activities at home.**

Delusions can be an ongoing, chronic problem. They are particularly hard to understand for family and caregivers when a person's cognition is still intact. A natural response is to try to explain or argue with the person experiencing delusions. However, there is no way to reason with a person through this experience. The thoughts are not voluntary. Instead, try to reassure the person that the consequences of their belief will not be catastrophic. You can't rationalize that what the person with Parkinson's is experiencing is not real even though at times they have clear thinking. You can't change a delusion. Try distraction: change the topic or involve the person in another activity. For example, if the person with Parkinson's claims that someone has stolen a pen, you can try to empathize and redirect: "Sorry to hear you lost your pen. Maybe we can try to find it later after we finish lunch."

If the person feels threatened, he or she may become argumentative, aggressive, agitated or unsafe, so it is not uncommon for family problems to arise. Remember, although the content of some delusional beliefs might be hurtful, the thoughts – and the actions that go along with them – are caused by the disease. It is Parkinson's talking, not your loved one. Listen attentively; try not to take offense; and be aware of your emotional response.

**George was at the drugstore when he noticed three men behind him. They didn't look like regular men. They had what appeared to be wicker skin. These "wicker men" followed him into his car and he drove back home with them. They didn't say anything; they just sat in the back seat. When he got home they didn't get out of the car. He didn't want to leave them in the car so he called his wife, Linda, to ask her what to do. Worried that there were strange men in George's car, she came outside but didn't see anyone in the backseat. They reported what George had been seeing to his doctor. The doctor decided they would keep an eye on the hallucinations to try to see if there was any pattern to when he experienced them. After a few days, George started seeing the "wicker people" in his house. He walked by his bedroom one night and found a "wicker man" lying next to his wife. He believed that his wife was cheating on him. Linda was unable to convince him that she was not. They went back to his doctor to describe how the hallucinations had changed and impacted their relationship. The doctor informed them that George was likely suffering from delusions, and Linda would not be able to explain away these beliefs because they are fixed in George's mind. The doctor prescribed an antipsychotic and after a few weeks, George was no longer worried that his wife was cheating.**

A caregiver support system is important. Allow others to help. Take time off for a break, and make sure you have someone to talk to. A support group can give you an outlet for your emotions along with some helpful tips. Having day-to-day help in the house; getting outside support from friends, family or professionals; and making a plan for the future can assist you in managing your time, resources and emotions.

Many people make promises to always care for their loved one themselves, at home. If you made this promise, you may not have understood all the responsibilities that caregiving entails. Caring for someone with hallucinations and delusions can be extremely difficult. At some point you may have to accept that it might not be possible to take care of your loved one at home anymore. In fact, one of the most common reasons for nursing home placement is non-remitting psychosis. At the same time, it can be difficult to find a placement for someone experiencing psychoses. Facilities that specialize in memory and dementia care cannot always handle the symptoms, and often people in this situation end up overmedicated. For suggestions on coping with PD psychosis and on caring for yourself, contact our Helpline at 1-800-4PD-INFO (473-4636) or [helpline@parkinson.org](mailto:helpline@parkinson.org).



# Summary

It is important to understand that psychosis results from a change in the brain's chemicals. Not everyone will experience psychosis, and you didn't cause the problem. The symptoms associated with a change in behavior and thinking require the same attention as your motor symptoms, like tremors and stiffness. People who are more active and social tend to experience these issues less often. Being isolated and withdrawn, or "destimulated," can increase the likelihood of experiencing symptoms. You and your family should be familiar with the symptoms of onset and the risks of treatment options. Discussing symptoms of mental illness with family, caregivers and clinicians is difficult for some, but early recognition of these mental and personality changes is important to effectively treat them and reduce fear and discomfort.



# Glossary

Glossary terms are identified with a blue underline the first time they appear in this book.

**A Acetylcholine** A chemical messenger (see neurotransmitter) released by cholinergic nerves; involved in many brain functions, such as memory and control of motor activity

**Aggression** Describes a range of angry or violent behaviors that can result in physical or emotional harm to yourself or others

**Agitation** Psychological or physical restlessness that can be a symptom of mental health disorders

**Alpha-synuclein** A protein in the human brain that is associated with the development of Parkinson's; it is the main component of Lewy bodies

**Alzheimer's disease** A neurodegenerative disorder that results in loss of memory, thinking and language skills and behavioral changes

**Anticholinergic** A substance that blocks the neurotransmitter acetylcholine in the central and peripheral nervous systems; typically the main ingredient in over-the-counter sleep aids and many allergy medications (e.g., Benadryl)

**Antipsychotic** A class of drugs used to treat symptoms of psychosis including hallucinations and delusions

**C Clozapine** Once considered the best antipsychotic medication for people with Parkinson's, but requires frequent blood tests because of 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

**Clozaril** Brand name for clozapine

**Confusion** A lack of understanding or clarity of thinking; can be caused by a medical condition and can be a short-term or permanent state

- D Delirium** A reversible medical condition that involves a change in the level of concentration or attention, disorganized thinking, unusual behavior and/or hallucinations; can be hard to differentiate from other psychiatric conditions
- Delusion** False, fixed, idiosyncratic beliefs, not substantiated by sensory or objective evidence; they are not deliberate and cannot be controlled
- Dementia** The term for a group of symptoms associated with a decline in memory and thinking
- Destimula ed** The act of calming one's environment by reducing environmental stressors including light, noise and activity; too much destimulation can lead to psychosis
- Dopamine** A chemical messenger (see neurotransmitter) that is primarily responsible for controlling movement, emotional responses and the ability to feel pleasure and pain; in people with Parkinson's, the cells that make dopamine are impaired or die
- H Hallucination** Something you see, hear, smell, taste or feel that is not actually there
- I Illusion** A sensory misperception when you misinterpret real external stimuli; e.g., mistaking hats on a coat rack for heads
- Insight** In the context of hallucinations, when you recognize that what you are seeing or hearing is not real
- J Jealous delusion** A type of delusion with the belief that your spouse or sexual partner is unfaithful
- L Levodopa** The medication most commonly given to control the motor symptoms of Parkinson's; it is converted in the brain into dopamine

**Lewy Body dementia (LBD)** Similar to Parkinson's disease dementia, but cognitive symptoms are present before or within one year of noticing the motor symptoms of Parkinson's; the central features of LBD include progressive cognitive decline, fluctuations in alertness and attention, visual hallucinations and parkinsonian motor symptoms, such as slowness of movement, difficulty walking or rigidity

**N Neurodegenerative disorder** A disease characterized by the loss of cells of the brain or spinal cord, which over time leads to dysfunction and disability; e.g., Parkinson's disease, Alzheimer's disease and Lou Gehrig's disease (ALS)

**Neurotransmitter** A chemical messenger, such as dopamine or acetylcholine, that transmits nerve impulses from one nerve cell to another, allowing them to communicate with each other

**Non-motor symptom** A symptom of Parkinson's that affects something other than movement, such as sleep, mood, behavior, sensory function (sense of smell, vision, pain) or autonomic function (urinary, gastrointestinal, sexual function); typically does not respond to dopamine-replacement therapy

**Nuplazid** Brand name for pimavanserin

**P Paranoia** A common type of delusion when you become suspicious

**Parkinson's disease dementia** A type of dementia that affects attention, recent memory, executive function and visual and spatial relations; about 25% of people with Parkinson's are affected, and it usually develops years after the PD diagnosis

**Parkinson's disease psychosis** A non-motor symptom of Parkinson's disease that causes you to experience hallucinations and/or delusions

**Parkinsonisms** A general term that refers to neurological disorders that affect dopamine levels and cause slowness of movement

**Passage hallucination** When an unformed object moves in your peripheral vision

**Persecutory delusion** A type of delusion when you think that harm is occurring or is going to occur

**Pimavanserin** A medication approved by the FDA in 2016 for the treatment of Parkinson's disease psychosis; it is a selective serotonin inverse agonist (SSIA) and targets serotonin receptors; this means it can reduce hallucinations without affecting movement

**Psychiatrist** A doctor that treats many common symptoms of Parkinson's that affect the mind (e.g., anxiety, depression, hallucinations); speaking with a psychiatrist is important for diagnosing and monitoring these symptoms, as they can also impact motor symptoms and disease progression

**Q Quetiapine** A medication used to reduce symptoms of psychosis; does not cause significant worsening of Parkinson's motor symptoms, but its efficacy has never been proven in Parkinson's

**R Rapid eye movement (REM) sleep behavior disorder** A sleep disorder in which you physically act out vivid, unpleasant dreams

**S Selective serotonin inverse agonist (SSIA)** A type of drug that specifically targets serotonin receptors and makes them do the opposite of their normal function

**Sense of presence** When you have the feeling of a person or animal being nearby when there is no one around

**Seroquel** Brand name for quetiapine

**Serotonin** A neurotransmitter that affects the regulation of mood, appetite and sleep

**Sinemet** Brand name for a drug combining carbidopa and levodopa that is used to treat Parkinson's motor symptoms (i.e., slowness, stiffness, tremor); comes in immediate- and extended-release forms

**Sleep apnea** A sleep disorder in which breathing repeatedly stops and starts

**Somatic delusion** A type of delusion related to bodily functioning or sensations, or physical appearance; the belief that the body is somehow diseased, abnormal or changed

**V Vivid dreaming** A dream that is very realistic and can be caused by awakening during the dream

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