

Guide to living with

Healthmonitor®

Parkinson's disease

Hallucinations? Delusions?
It could be Parkinson's disease psychosis (PDP)

*Fortunately, PDP is treatable—
talk to your doctor today!*

FEEL YOUR BEST

- ✓ Keep track of your symptoms
- ✓ Learn about your treatment options
- ✓ Ask these questions, p. 24
- ✓ Get inspired by others with PD

**"I reached out for help—
now, I'm doing great!"**

Opening up to his doctor and getting the right treatment helped Dan Cotton come out on top of some worrisome symptoms

COMPLIMENTS OF YOUR HEALTHCARE PROVIDER

FREE
take-home
copy

 Parkinson's
Foundation

Guide to living with Parkinson's disease



8

"PDP doesn't have to hold you back," says Dan, who is living proof since finding the right treatment.

The basics

- 4 **Live your best life!**
Learn about Parkinson's disease and the therapies that can help you manage your symptoms

You & your care team

- 7 **Meet your care team**
- 10 **Report your symptoms**
Fill out this tool and share it with your doctor
- 19 **The help you need**
Reach out for information and support
- 23 **Ask the expert**
Neurologist and Parkinson's disease expert Adolfo Ramirez-Zamora, MD, answers your questions
- 24 **Questions to ask your care team**

True inspiration

- 8 **"I want to help others with PDP!"**
Dan Cotton says his quality of life improved when he opened up to his doctor
- 20 **"We're doing what we love!"**
Michelle, Sharon and Nikki share the strategies that help them stay healthy and active

Special section on Parkinson's disease psychosis

- 11 **Understanding Parkinson's disease psychosis (PDP)**



20 Sharon, above with husband Joel, and Michelle, left, say regular exercise is key to maintaining strength and mobility.

- 16** Could you, or your loved one, have PDP?
Fill out and share this worksheet with your neurologist
- 17** Questions for your doctor about PDP
Bring these questions to your next exam
- 18** How PDP is treated
Learn about the steps that can help

SPECIAL THANKS TO

Adolfo Ramirez-Zamora, MD

Associate professor of neurology and director of clinical trials at the University of Florida, Fixel Center for Neurological Diseases



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure.

Healthmonitor®

Vice President, Editor-In-Chief
Maria Lissandrello

Managing Editor **Lindsay Bosslett**

Senior Editors **Kathleen Engel, Karen Kleimann**

Senior Associate Editor **Joana Mangune**

Vice President, Creative Director
John Angelini

Senior Art Director **Jennifer Webber**

Graphic Designer **Ashley Pinck**

Associate Graphic Designer
Molly Cristofolletti

Vice President, Production and Project Management **Kimberly H. Vivas**

Production and Project Manager
Jennie Macko

Director of Financial Planning and Analysis
Dawn Vezirian

Financial Controller **Angelica Mariscal**

Sales Director **Fabrizio Gambino**

Vice President, Sales **Mike Weiss**

Senior Vice President, Advocacy and Alliances **Chris O'Toole**

Chief Marketing Officer **Rodnell E. Workman**

Chief People Officer **Joe DiCarlo**

Chief Commercial Officer **Paul Wituschek**

Chief Financial Officer **Howard Halligan**

Senior Vice President, New Products, Technology and Strategy **Alex Dong**

Chief Executive Officer **Kenneth Freirich**

Health Monitor Network is the nation's leading multimedia patient-education company, with websites and publications such as *Health Monitor*®. For more information: Health Monitor Network, 135 Chestnut Ridge Road, Montvale, NJ 07645; 201-391-1911; healthmonitor.com ©2019 Data Centrum Communications, Inc. Questions? Contact us at customerservice@healthmonitor.com

This publication is not intended to provide advice on personal matters, or to substitute for consultation with a physician.

NUJ19

LIVE YOUR *best* LIFE!

If you've been diagnosed with Parkinson's disease, take heart: Today's treatments are helping people with the condition survive—and thrive—for years!

When Bruce Ballard slices his way through the water in a freestyle swim competition, Parkinson's disease (PD) is not on his mind. "I've always been a competitive swimmer, and in the summer I usually enter a few open-water races in the Atlantic Ocean, the Hudson River, Lake George and elsewhere," says Bruce, who typically wins his age group. "The distances usually range from one to two miles, and I always feel great after them."

Besides potentially helping to stall the progress of the disease, Bruce finds exercise has another huge benefit: It erases the anxiety that often plagues him and bothers many others with PD.

"At this stage of my life with the disease [he was diagnosed 13 years ago], it's all about finding ways to beat the challenges," says Bruce, who lives in Westchester, NY, with his husband, Yong Ih. Consider that his days start with a 4 AM wake-up call to take his first round of PD meds. By 5:15 he's out of the house to make the 40-minute drive to the Bronx, where he's a staff trainer at a charter school. After work, he heads home for Ping-Pong at a nearby table

tennis center ("a surprising mental and physical challenge"), a run or a trip to the gym, which might include an hour on the spin bike, pedaling at 100 rpm—after which, he says, "for the next 48 hours or so, I'm hardly aware I have PD."

Although he turns in at 8 PM, sleep doesn't always come easy. When insomnia, another common PD symptom, keeps him up, he may lie in bed and "write" a haiku (a three-line poem), counting the syllables on his fingers in the dark. (Bruce just published 100 haikus about PD on his blog, parkingsuns.com.)

How does he do it all? Bruce credits an effective treatment plan, the support of Yong Ih and an "absolutely terrific" movement disorder specialist for the full, active life he enjoys. If you have PD and feel you've been settling for a lesser life, follow Bruce's lead: Start by reading this guide, then have a heart-to-heart with your healthcare team to discuss ways you can make every day better!

What is Parkinson's disease?

Parkinson's is a chronic neurodegenerative disorder that

typically progresses slowly over time and affects a person's ability to control their movements. It occurs when neurons, or nerve cells, in an area of the brain known as the *substantia nigra* break down or die off. These neurons produce a neurotransmitter (a brain chemical that communicates information throughout the brain and body) called dopamine that helps regulate movement and coordination, and which also causes non-motor symptoms, such as sleep problems and anxiety. As less and less dopamine is produced, Parkinson's symptoms arise, often starting out subtle and gradually worsening.

Researchers have also associated other brain changes with Parkinson's. These include Lewy bodies, which are clumps of a protein called alpha-synuclein. They can be found in various areas of the brain, and scientists believe they may be connected to the cause and progression of Parkinson's disease symptoms.

Who is at risk?

Approximately 60,000 new cases are diagnosed each year in the United States. Men are 1.5 times more likely



than women to have PD. Symptoms most often begin to appear after age 60, but there is a specific type called young-onset Parkinson's that is diagnosed earlier.

We do not know exactly what causes PD, but scientists believe

that a combination of genetic and environmental factors may be the cause. The extent to which each factor is involved varies from person to person. From 10% to 15% of all

cases are thought to be primarily genetic—the most common being a mutation that occurs more frequently in people of North African or Jewish descent. And while having a close relative with Parkinson's does raise the chances of developing the disease, the increased risk is small unless many people in the family have been diagnosed. Potential environmental triggers include significant ongoing exposure to certain pesticides, herbicides and heavy metals.

There's no specific test to diagnose Parkinson's—instead, neurologists assess signs and symptoms, review your medical history and complete a detailed neurological exam. A main goal is to rule out other diagnoses.

Spotting the signs

Parkinson's symptoms can vary widely from person to person. Often, they start out so mild as to go unnoticed. Once noticeable, they typically tend to begin on one side of the body. The four main motor (movement-related) symptoms are:

- **Resting tremor.** Involuntary shaking that affects a limb when at rest, it usually first occurs in a hand or finger and improves when performing tasks.
- **Slowness of movement.** This symptom, also called bradykinesia, may be accompanied by a shuffling gait; reduced facial expressiveness (called hypomimia, or facial masking); and fine-motor problems such as difficulty buttoning a shirt.
- **Stiffness.** Unusually tight or achy muscles may occur in any part of the body and can limit your range of motion.
- **Postural instability.** Being unstable when you're on your

feet results in issues with balance, walking and turning around. As a result, falls are a concern.

Parkinson's patients also may experience non-motor symptoms that can include:

- **Hyposmia**, or the loss of sense of smell
- **Constipation and bladder problems**
- **Sleep disturbances**, such as waking up frequently at night, acting out dreams (REM sleep behavior disorder) and daytime drowsiness
- **Mood disorders**, including

depression or anxiety

- **Orthostatic hypotension**, or low blood pressure when standing up, which can cause lightheadedness and dizziness
- **Cognitive changes**, such as difficulty concentrating or multitasking

Taking charge of treatment

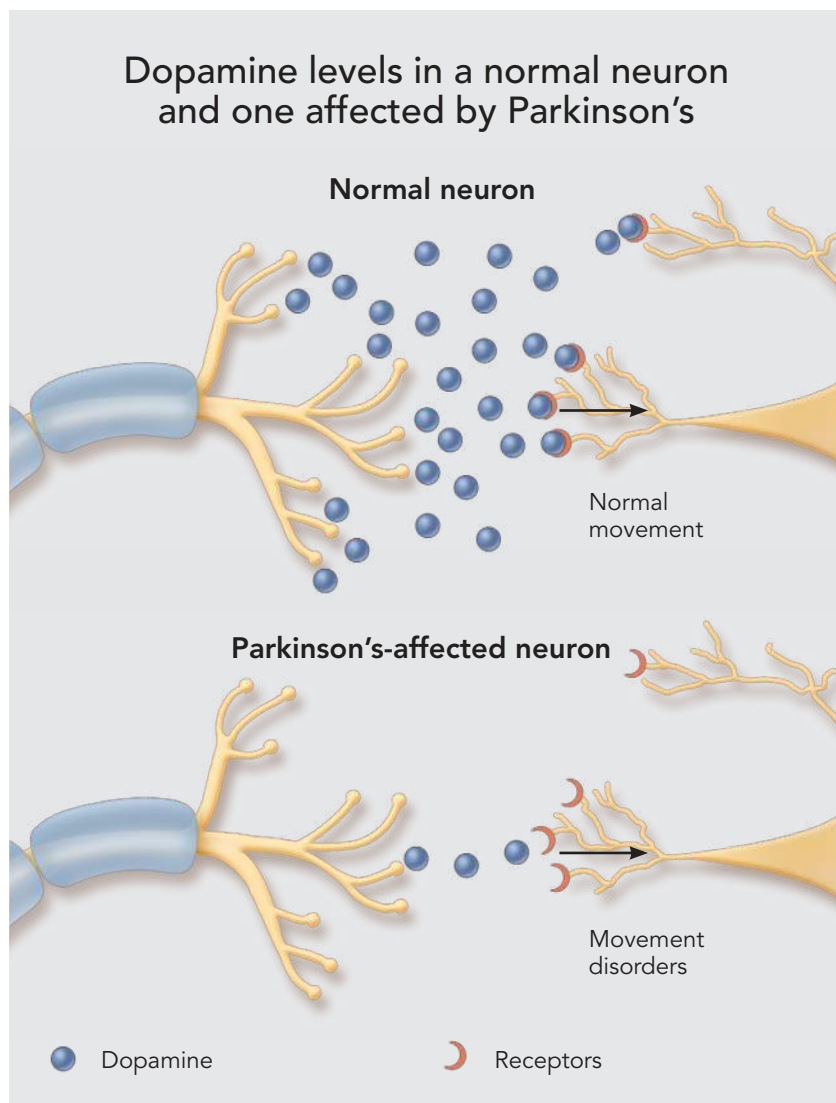
While there is currently no cure for Parkinson's, there is much you can do to manage your symptoms, and it's important to work with your healthcare team to develop a

personalized treatment strategy that's right for you. Early treatment has been shown to improve quality of life, and reporting all symptoms is key—especially as new treatments in the pipeline can improve the long-term prognosis for patients.

MEDICATIONS

The main aim of Parkinson's medications is to compensate for the lack of dopamine that causes symptoms.

- **Levodopa** was developed in the 1960s and is still the most commonly used Parkinson's medication. It passes into your brain, where it's converted into dopamine. It's frequently combined with another drug called carbidopa, which helps prevent levodopa from breaking down before it can be converted in your brain. Over time, the brain can have a fluctuating response to levodopa, often referred to as "on" and "off" periods in which the drug's effectiveness varies.
- **Dopamine agonists** don't convert to dopamine like levodopa does; instead, they mimic dopamine in your brain. While their effectiveness may not be comparable with levodopa as the disease progresses, their effects tend to last longer and so they're sometimes used in conjunction with levodopa to ease that drug's on and off periods.
- **Amantadine** is sometimes used on its own to treat the mild symptoms of early-stage Parkinson's or in combination with levodopa to treat dyskinesias (involuntary twisting or writhing movements), which can be associated with that drug.
- **Anticholinergics** work to block acetylcholine, a neurotransmitter that regulates movement, helping to ease motor symptoms such



as tremors and dystonia (painful muscle contractions).

- **COMT inhibitors** are used in combination with levodopa and prolong its effects by blocking an enzyme that breaks down dopamine.
- **MAO-B inhibitors** work to inhibit a brain enzyme that naturally breaks down dopamine in the brain; they're used alone or in conjunction with levodopa.

SURGERY

When medications don't adequately control symptoms, deep brain stimulation (DBS) may be an option for some patients. The surgery involves implanting a device called a neurostimulator that delivers electrical impulses to areas of the brain, helping to block signals that cause tremors and other Parkinson's symptoms.

LIFESTYLE CHANGES

- **Eat a healthy diet.** Staying hydrated and getting adequate fiber can help combat digestive

problems. Work with your doctor about timing meals and meds; certain foods can affect how well your body absorbs drugs.

- **Avoid falls.** Be proactive: Avoid carrying things while walking, and make wide U-turns instead of pivoting on your feet. At home, secure rugs and loose cords.
- **Create a support system.** Whether it's friends, family or a PD support group, connecting with others can help.
- **Stay active.** Exercises like walking, swimming and yoga bolster strength, flexibility and balance. Moderate cardio exercise can also improve memory and reduce symptoms. A physical therapist can help you create an appropriate fitness routine.

Parkinson's symptoms can change over time, so keep up to date with your care team. As more treatment options are available than ever before, there's much you and your doctor can do to ensure you're able to live your life to the fullest! 🍷

Meet your healthcare team

These healthcare professionals can help ensure you find the right treatment plan:

- **Primary care provider:** This MD can address a number of health-related concerns and will help coordinate your care with referrals to the appropriate specialists.
- **Neurologist:** Specializing in disorders of the nervous system, this physician may diagnose your Parkinson's and will likely develop your treatment plan and help you manage symptoms.
- **Movement disorder specialist:** This is a neurologist who has received additional specialized training in movement disorders like Parkinson's. Often affiliated with a major university or teaching hospital, they are up-to-date on the latest cutting-edge treatments.
- **Neuropsychologist:** This physician combines specialties of neurology and psychiatry to treat and manage the emotional and cognitive symptoms of neurological diseases like Parkinson's.
- **Physical therapist:** A PT will create an exercise regimen that helps strengthen your muscles and improve your balance.
- **Occupational therapist:** This therapist will help you assess your living and work environments, recommending modifications that can improve your quality of life.
- **Speech-language pathologist:** This specialist can help with any problems with swallowing or speech, including speaking too softly or slurring words.
- **Social worker:** These professionals offer counseling services and can resolve issues with insurance, housing and more.

Hallucinations? Delusions? Speak up! NOW THERE'S HELP!

Tremors and slow movement may be hallmark signs of Parkinson's, yet other symptoms can be underreported. Two that often go undisclosed: hallucinations and delusions. It's not uncommon for PD patients to experience these signs of Parkinson's disease psychosis (PDP) over time or later in the disease, yet many do not tell their doctors about them. In most cases, hallucinations (seeing, hearing or feeling something that's not there) and delusions (irrational views not based in reality) occur as a side effect of Parkinson's medications used to treat motor symptoms. Unfortunately, treating the psychosis with antipsychotic medications can cause Parkinson's disease symptoms to worsen.

The good news? Medication is now available that treats PDP without interfering with frontline Parkinson's disease medications. In fact, the Food & Drug Administration approved the drug pimavanserin for the treatment of Parkinson's disease psychosis. Find out more about PDP and how you can alleviate the symptoms starting on p. 11.

“I have PD psychosis—and I want to help others with

By opening up to his doctor, Dan was relieved to find there was help for the condition that baffled him. —BY AMY CAPETTA

There’s no denying that Dan Cotton is living a full and active life. On any given day, the 54-year-old from Port Charlotte, FL, can be found either fishing, volunteering, keeping busy around the house, or socializing with friends. So it may come as a surprise to learn that Dan has been living with Parkinson’s disease (PD) for close to six years.

His health journey goes back to 2013, when Dan noticed a tremor in his right hand. “I drank a lot of coffee and iced tea throughout the day, so I

thought I was taking in too much caffeine,” says the retired police officer. When switching to decaf beverages didn’t eliminate the shaking, he made an appointment with a neurologist.

It was during this 75-minute visit that Dan was diagnosed with PD, a progressive brain disorder that results in shaking and stiffness, as well as difficulty with walking and coordination. He was stunned. “I had never met anyone who had Parkinson’s,” he says. The neurologist prescribed a medication

that reduced the tremors—so much so that his trembling hand was barely noticeable. In fact, his nearly 30-year law enforcement career ended only in September 2016, following a minor car accident.

It was a year after that—in 2017—that the condition took an unexpected turn.

“I saw shadows and heard voices”

Dan recalls a number of occasions when he’d be on the computer

“My family has been my greatest support system,” says Dan, with his wife, Bobbi Jo, and sons Kyle (left) and Harley.



now the condition!”

in his home office and hear his wife, Bobbie Jo, calling his name from another room. But when Dan asked her what she wanted, Bobbie Jo said she hadn't said a thing. More troubling, he started seeing shadows out of the corner of his eye that resembled either a mouse or small animal running by and hearing the voices of former co-workers—people who lived over 1,000 miles away in Baltimore. “They'd say something like, ‘Why are you doing something this

way?’ and I'd respond as if we were having a conversation,” he says. When Dan's wife poked her head in the room, he'd stop talking—he wanted to keep these moments to himself, he says.

“I know I saw him sitting there!”

For the next four months, these “interactions” became more frequent and more vivid. Eventually, paranoia set in. “I thought I was being followed, and I told Bobbie Jo there was a camera on a telephone pole outside of our house.” To prove his point, Dan took photos of the pole and enlarged the images—but the camera didn't exist.


At one point, Dan was driving in his truck when his older brother suddenly “appeared” in the passenger seat. “He was giving me directions,” says Dan. “I turned to look at the traffic light, and when I looked to my right again, he was gone. I thought, *I know I saw him sitting there!*”

“I was ready to give this med a try!”

During an appointment with his neurologist, Dan confessed everything. (“My wife found out at the same time as my doctor,” he admits.) His doctor urged him to visit a psychiatrist, who diagnosed him in their first session—Dan had PD psychosis, a non-motor symptom of Parkinson's disease that causes hallucinations and delusions

(and, in some cases, nightmares). “Not only did she tell me it was a common symptom but that there was a fairly new medication on the market that was specifically designed for the condition. I was ready to give it a try!”

Within weeks of starting the therapy, Dan noticed that his hallucinations were dramatically reduced. “Plus, I had no side effects and it worked well with my other meds,” he says. Today, Dan continues to take the medication and says his only remaining symptom is occasionally “hearing” a radio or TV in the background (that isn't actually on). “To me, this is nothing!”

With the goal of spreading awareness about PD psychosis, Dan volunteers as an ambassador at the Neuro Challenge Foundation, a non-profit organization in Sarasota, FL, where he meets other patients with PD psychosis who “tend to be secretive about it, just like I was for all those months.” His number one message for other PD patients: Be honest with yourself, as well as with those in your inner circle. “If you don't come clean, your quality of life—and your caregiver's quality of life—deteriorates,” he says. “At the very least, tell your doctor about any problem you're dealing with so the two of you can address it together. I honestly don't know where I'd be right now if I continued to keep my hallucinations to myself.” 



Report your symptoms

Managing Parkinson's disease can be challenging, but finding the right treatment plan can make all the difference. Fill out this tool and share it with your care team to make sure you're doing all you can to thrive.



Having trouble answering these? Ask your caregiver for help.

1. My motor symptoms

Indicate: **1** (not a problem), **2** (moderate problem), **3** (challenging) or **4** (severe).

- Stiffness or rigidity
- Tremor or shakiness
- Freezing in position while walking
- Balance problems or falls (postural instability)
- Low voice or muffled speech
- Lack of facial expression
- Stooped posture
- Swallowing problems
- Twisting or writhing movements (dyskinesias)

2. My non-motor symptoms

Indicate: **1** (not a problem), **2** (moderate problem), **3** (challenging) or **4** (severe).

- Urinary problems (including incontinence and frequent or urgent urination)
- Drooling, excess saliva
- Hallucinations
- Fatigue
- Vision problems
- Memory difficulties
- Reflux
- Changes in taste or smell (circle which)
- Mood problems, including anxiety, depression and irritability (circle which)
- Bowel problems (including constipation and feeling full after eating small amounts)
- Delusions
- Pain
- Sexual difficulties
- Impaired cognition (thinking)
- Dizziness or lightheadedness when standing
- Poor appetite or weight loss
- Trouble sleeping, including insomnia, restless legs, nightmares or vivid dreams, excessive drowsiness

3. How difficult are everyday activities?

Rate the following on a scale from **1** (easy to do) to **5** (unable to do).

- Getting out of bed in the morning
- Dressing and undressing myself
- Moving around my home
- Rising from a chair unassisted
- Bathing and grooming myself
- Cutting meat and raising a glass to my mouth
- Doing housework like vacuuming and making beds
- Participating in leisure activities (e.g., dining out, movies, walks, travel)

4. How do PD symptoms affect your life?

Indicate: **1** (never), **2** (sometimes), **3** (often) or **4** (almost always).

- I feel stressed, anxious or depressed.
- I feel very confused.
- I feel unable to do things I used to on my own.
- I experience flashbacks.
- I find it a challenge just to get through the day.
- Bathing and grooming myself are difficult.
- I have trouble sleeping or have nightmares.
- I feel out of touch with reality.
- I see friends and loved ones less than I used to.
- I feel paranoid.
- I have trouble controlling my impulses (e.g., gambling, binge eating).

Understanding Parkinson's disease psychosis

Chemical and physical changes in the brain may trigger this condition, which occurs in some people who have Parkinson's disease. Fortunately, there is treatment. —BY DIANA WHELAN

If you or someone you love has Parkinson's disease, you're likely familiar with its hallmark motor symptoms—tremors, slow movement, limb stiffness and balance problems. But you may not be aware of the symptoms that can have an even greater impact on quality of life for the person with Parkinson's—the non-motor (non-movement related) disturbances that include hallucinations and delusions, called Parkinson's disease psychosis (PDP).

Some people who have Parkinson's disease will develop PDP symptoms over the course of their disease. Unfortunately, those who experience these symptoms may not report them to their doctor, either because they don't realize they're related to Parkinson's disease, or because they're too embarrassed to bring them up.

What are the signs of PDP?

- **Hallucinations.** Visual hallucinations are the most common symptom of PDP and occur in up to one third of people with Parkinson's. A person may “see” something that isn't real—say, an animal in the bed. Also common are “presence” hallucinations—a sensation that something or someone is nearby.

“As hallucinations become more severe over time, they become more formed and morph into people or animals,” says Okeanis Vaou, MD, assistant professor of neurology, Boston University School of Medicine. “Hallucinations are more likely to occur in the evening.



Sometimes exposure to light or sound can temporarily lead to improvement.”

- **Delusions.** Nearly one out of 10 people with PD experiences delusions, or false beliefs, such as thinking someone is breaking into the house. Often, the person who has delusions becomes paranoid—for example, accusing their spouse of being unfaithful. Delusions usually begin as general confusion and can progressively worsen.


- **Other symptoms.** Some people with PDP experience auditory hallucinations, or false perceptions of sound, such as hearing faint talking or the radio (when it's turned off); these are less common than visual hallucinations. Hallucinations involving smelling, feeling or tasting are rare in PD.

What causes PDP?

Medication, dementia and delirium are the three main contributors to

the development of PDP. Dopamine therapy, a mainstay of PD treatment that replenishes levels of dopamine or mimics its actions, can elicit psychotic symptoms, while brain changes that occur as PD becomes more severe can also lead to psychosis. Not surprisingly, PDP is most often seen in people who have had PD for more than five years. People with Parkinson's-related dementia and those who have cognitive dysfunction (problems with thinking and remembering) may also be more likely to develop PDP symptoms as are those who have depression or sleep disorders.

What you can do about it

If you or your loved one has ever experienced a hallucination or delusion, let your doctor know in order to get the help that can make a difference. Read about the treatment options on p. 18. 

Seeing and hearing things
that others don't?

Believing things
that aren't true?

Don't keep it in.

AROUND 50% OF PEOPLE WITH PARKINSON'S MAY
EXPERIENCE HALLUCINATIONS AND/OR DELUSIONS
DURING THE COURSE OF THEIR DISEASE.

NUPLAZID® IS THE ONLY FDA-APPROVED MEDICINE PROVEN TO REDUCE THE FREQUENCY AND/OR SEVERITY OF HALLUCINATIONS AND DELUSIONS RELATED TO PARKINSON'S

Indication and Important Safety Information for NUPLAZID (pimavanserin)

NUPLAZID is a prescription medicine used to treat hallucinations and delusions associated with Parkinson's disease psychosis.

WARNING: INCREASED RISK OF DEATH IN ELDERLY PATIENTS WITH DEMENTIA-RELATED PSYCHOSIS

- Medicines like NUPLAZID can raise the risk of death in elderly people who have lost touch with reality (psychosis) due to confusion and memory loss (dementia).
- NUPLAZID is not approved for the treatment of patients with dementia-related psychosis unrelated to the hallucinations and delusions associated with Parkinson's disease psychosis.
- **Do not take NUPLAZID if you** have had an allergic reaction to any of the ingredients in NUPLAZID. Allergic reactions have included rash, hives, swelling of the tongue, mouth, lips, or face, throat tightness, and shortness of breath.
- **NUPLAZID may cause serious side effects including:**
 - **QT Interval Prolongation:** NUPLAZID may increase the risk of changes to your heart rhythm. This risk may increase if NUPLAZID is taken with certain other medications known to prolong the QT interval. **Tell your healthcare provider about all the medicines you take or have recently taken.**
 - Do not take NUPLAZID if you have certain heart conditions that change your heart rhythm. It is important to talk to your healthcare provider about this possible side effect. Call your healthcare provider if you feel a change in your heartbeat.



Actor portrayal



- **Tell your healthcare provider about all the medicines you take.** Other medicines may affect how NUPLAZID works. Some medicines should not be taken with NUPLAZID. Your healthcare provider can tell you if it is safe to take NUPLAZID with your other medicines. Do not start or stop any medicines while taking NUPLAZID without talking to your healthcare provider first.
- The **most common side effects** of NUPLAZID include swelling in the legs or arms, nausea, confusion, hallucination, constipation, and changes to normal walking. These are not all the possible side effects of NUPLAZID. For more information, ask your healthcare provider about this medicine.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

You can also call ACADIA Pharmaceuticals Inc. at 1-844-4ACADIA (1-844-422-2342).

Dosage and Administration

The recommended dose of NUPLAZID is 34 mg capsule once per day, taken by mouth.

NUPLAZID is available as 34 mg capsules and 10 mg tablets.

Please see Brief Summary of Important Information on reverse side.

Ask your Parkinson's Specialist about NUPLAZID

NUPLAZID.COM 833-NUPLAZID

ONCE-DAILY
NUPLAZID[®]
(pimavanserin) 34mg capsules

Brief Summary of Important Information About NUPLAZID[®] (pimavanserin) (new-PLA-zid)

What is NUPLAZID used for?

NUPLAZID is a prescription medicine used to treat hallucinations (such as seeing or hearing things that others do not) and delusions (such as believing things that are not true) associated with Parkinson's disease psychosis in adults. It is not known if NUPLAZID is safe and effective in people under 18 years of age.

What is the most important information I should know about NUPLAZID?

- **Increased risk of death in elderly patients with dementia-related psychosis: Medicines like NUPLAZID can raise the risk of death in elderly people who have lost touch with reality (psychosis) due to confusion and memory loss (dementia).**
- **NUPLAZID is not approved to treat patients with dementia-related psychosis unrelated to the hallucinations and delusions associated with Parkinson's disease psychosis.**

Who should not take NUPLAZID?

Do not take NUPLAZID if you are allergic to pimavanserin or any of the other ingredients in NUPLAZID. Get emergency medical help if you are having an allergic reaction. Symptoms may include:

- rash
- throat tightness
- hives
- shortness of breath
- swelling of the tongue, mouth, lips, or face

NUPLAZID may increase the risk of certain changes to your heart rhythm. Therefore, do not take NUPLAZID if:

- You have certain heart conditions that change your heart rhythm, or
 - known QT prolongation as measured on an ECG (a device that traces the electrical activity of the heart)
 - a history of certain irregularities of heart rhythm (discuss the specifics with your doctor)
- You are currently taking medicines that are known to prolong the QT interval. Ask your healthcare provider if you are not sure if you are taking any of these medicines. Examples include:
 - some medicines used to treat abnormal heart rhythms (for example, quinidine, procainamide, amiodarone, sotalol)
 - some antipsychotic medicines (for example, ziprasidone, chlorpromazine, thioridazine)
 - some antibiotics (for example, gatifloxacin, moxifloxacin)

Call your healthcare provider if you feel any symptoms of heart arrhythmia (for example, fluttering in chest, racing or slow heartbeat, chest pain, shortness of breath, lightheadedness or dizziness, or fainting).

What should I tell my healthcare provider before taking NUPLAZID?

Before taking NUPLAZID, tell your healthcare provider if you:

- have heart problems
- take medicines that affect the way certain liver enzymes work. Ask your healthcare provider if you are not sure if your medicine is one of these.
- are pregnant or plan to become pregnant. It is not known if NUPLAZID may harm your unborn baby.

Tell your healthcare provider about all the medicines that you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How should I take NUPLAZID?

- Take NUPLAZID exactly as your healthcare provider tells you to take it. Do not change the dose or stop taking NUPLAZID without talking to your healthcare provider first.
- The recommended dose is 34 mg once per day, taken by mouth.
- NUPLAZID can be taken with or without food.

What are the possible side effects of NUPLAZID?

Common side effects include:

- swelling in the legs or arms
- hallucinations
- nausea
- constipation
- feeling confused
- changes to normal walking

These are not all the possible side effects of NUPLAZID.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You can also call ACADIA Pharmaceuticals Inc. at 1-844-4ACADIA (1-844-422-2342).

General information about NUPLAZID

This is a brief summary of risk and safety information for patients about NUPLAZID. This information is not comprehensive and does not take the place of talking to your doctor about your treatment. To learn more, talk about NUPLAZID with your healthcare provider. The FDA-approved Full Prescribing Information can be found at www.NUPLAZID.com or 1-844-4ACADIA (1-844-422-2342).

Experiencing Parkinson's-related hallucinations and delusions? Don't keep it in.

Here are a few statements to help you and your loved one start the conversation with your healthcare provider.

- Have seen, heard, or sensed things, such as people, animals, or objects, that were not actually there (hallucinations).
- Have had false beliefs or fears that someone (perhaps a spouse, caregiver, or friend) is stealing or being unfaithful (delusions).
- These experiences have been shared with loved ones.
- Daily routine has changed as a result of experiencing hallucinations or delusions.



Actor portrayal

Ask your healthcare provider about **NUPLAZID**[®]—the only FDA-approved medicine proven to reduce the frequency and/or severity of hallucinations and delusions related to Parkinson's.

Indication and Important Safety Information for NUPLAZID (pimavanserin)

NUPLAZID is a prescription medicine used to treat hallucinations and delusions associated with Parkinson's disease psychosis.

WARNING: INCREASED RISK OF DEATH IN ELDERLY PATIENTS WITH DEMENTIA-RELATED PSYCHOSIS

- Medicines like NUPLAZID can raise the risk of death in elderly people who have lost touch with reality (psychosis) due to confusion and memory loss (dementia).
- NUPLAZID is not approved for the treatment of patients with dementia-related psychosis unrelated to the hallucinations and delusions associated with Parkinson's disease psychosis.
- **Do not take NUPLAZID if you** have had an allergic reaction to any of the ingredients in NUPLAZID. Allergic reactions have included rash, hives, swelling of the tongue, mouth, lips, or face, throat tightness, and shortness of breath.
- **NUPLAZID may cause serious side effects including:**
 - **QT Interval Prolongation:** NUPLAZID may increase the risk of changes to your heart rhythm. This risk may increase if NUPLAZID is taken with certain other medications known to prolong the QT interval. **Tell your healthcare provider about all the medicines you take or have recently taken.**
 - Do not take NUPLAZID if you have certain heart conditions that change your heart rhythm. It is important to talk to your healthcare provider about this possible side effect. Call your healthcare provider if you feel a change in your heartbeat.

- **Tell your healthcare provider about all the medicines you take.** Other medicines may affect how NUPLAZID works. Some medicines should not be taken with NUPLAZID. Your healthcare provider can tell you if it is safe to take NUPLAZID with your other medicines. Do not start or stop any medicines while taking NUPLAZID without talking to your healthcare provider first.

- The **most common side effects** of NUPLAZID include swelling in the legs or arms, nausea, confusion, hallucination, constipation, and changes to normal walking. These are not all the possible side effects of NUPLAZID. For more information, ask your healthcare provider about this medicine.

Dosage and Administration

The recommended dose of NUPLAZID is 34 mg capsule once per day, taken by mouth.

NUPLAZID is available as 34 mg capsules and 10 mg tablets.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

You can also call ACADIA Pharmaceuticals Inc. at 1-844-4ACADIA (1-844-422-2342).

Please see Brief Summary of Important Information on the previous page.

Could you, or your loved one, have Parkinson's disease psychosis?

Some people don't report hallucinations or delusions, if they have them, to their doctor. Yet it's important to speak up about these symptoms of Parkinson's disease psychosis (PDP), since the condition *is* treatable. You can take the first step toward getting relief from PDP by filling out this worksheet and reviewing it with your neurologist.



If you are a caregiver, friend or family member, check off the appropriate responses for your loved one, or fill in the blank where appropriate.

Your health status

- I've had Parkinson's disease for ____ years.
- I've recently had an infection or stroke.
- I frequently experience depression and/or anxiety.

The symptoms (check all that apply)

- Seeing things that aren't there, such as people, animals or objects
- Feeling as if there's a presence in the room when there isn't
- Hearing sounds that aren't real
- Tasting or smelling something that doesn't exist
- Feeling like someone is out to get you, to steal from you or cheat on you
- Having vivid nightmares and/or flashbacks
- Feeling you are being monitored, or that people are talking about you
- Intense irritability

I experience hallucinations or delusions (check one):

- Several times a day (please estimate how many times per day): _____
- Once a day
- A few times a week
- Once a week
- Once or twice a month

Hallucinations or delusions most often occur (check one):

- At night
- In the afternoon
- In the morning

Medications

I'm taking these medications for my Parkinson's and my symptoms: _____

Questions for your neurologist about Parkinson's disease psychosis

If you have PDP, getting the best possible care means talking openly with your doctor about it. Get the conversation started with these questions:

1. Could my symptoms mean that I have Parkinson's disease psychosis (PDP)?
2. Should we run any tests to determine if I have an infection that could be causing my symptoms?
3. Do you recommend that I speak with a counselor or psychologist?
4. What treatment do you recommend and why? What are the risks and benefits?
5. How do we make sure that my treatment is on track?
6. Are there any lifestyle changes I can make to prevent hallucinations or delusions?
7. Are there things I can do that might help make my life safer and less stressful?
8. When will my symptoms start to improve?
9. What symptoms or side effects should I report to you?

What your neurologist needs to know

You can help your doctor provide the best possible care by supplying some important information. Fill this out and review during your exam.

1. Prescription or over-the-counter medications you're currently taking or have taken in the past:

2. Allergies to any medications (please list): _____

3. What year you were diagnosed with Parkinson's disease: _____
4. When symptoms of Parkinson's disease psychosis (hallucinations and/or delusions) began:

5. Number of hallucinations or delusions you experience in a typical week:
Hallucinations: _____ Delusions: _____ Or check: I am not sure.



There's help for PDP!

That means there's more reason than ever for you (or your caregiver) to talk to your doctor about the unsettling symptoms! Read on.



Hallucinations and delusions can be frightening and unpleasant for the person living with Parkinson's disease psychosis (PDP). And yet, it's not uncommon for people with PD and their care partners to keep quiet about these symptoms. But there's no need to keep silent! Your healthcare team can help you find a method that can treat these symptoms—here is what you can expect.

Partnering with your care team

The first thing your doctor will do if they suspect you have PDP is perform a clinical evaluation of your symptoms including your prior medical history, disease stage and available support

systems. This will help determine if you need treatment right away, or if you can keep an eye on the condition and wait.

Step-by-step strategy


If it's determined your PDP warrants treatment right away, the first step is typically adjusting your PD medications, since PDP is often caused by PD treatments themselves. Your doctor may also recommend you work with a counselor to deal with the emotional impact of PDP.

If further intervention is needed, your doctor may consider using behavioral techniques in addition to memory enhancers (cholinesterase inhibitors). Other medications, such as

atypical antipsychotics, may be used in certain situations to rebalance the chemical levels in the brain and reduce episodes of hallucinations and delusions.

However, there's a downside: These options may cause the motor symptoms of PD to return.

A breakthrough option

If the steps described above don't work for you, take heart: The first medication to treat PDP that does not aggravate motor symptoms, pimavanserin, has been shown to reduce the frequency and severity of hallucinations and delusions by targeting serotonin receptors instead of dopamine. Ask your doctor if this breakthrough drug may be an option for you. 

The resources you need now!

Are you looking for more information on Parkinson's disease? Hoping to connect with others who understand you? These organizations can help!



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community. Visit Parkinson.org to learn more.

Other places to turn:

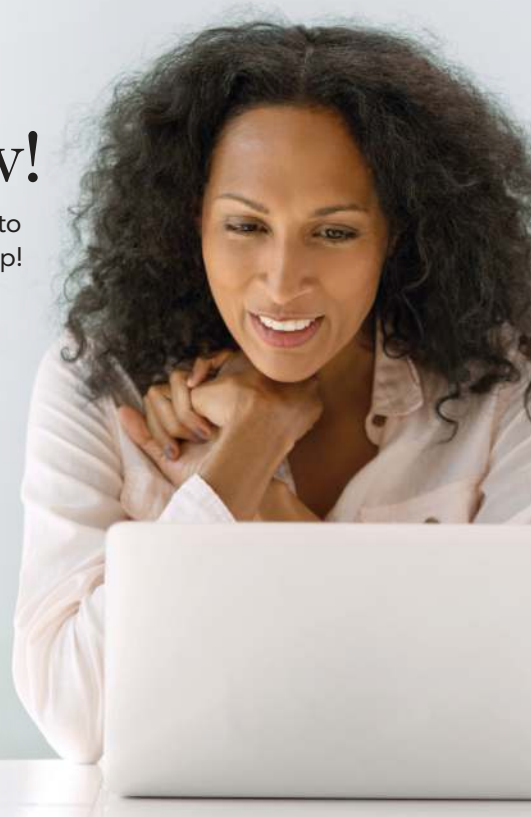
American Parkinson's Disease Association
www.apdaparkinson.org

Michael J. Fox Foundation
www.michaeljfox.org

The Davis Phinney Foundation
www.davisphinneyfoundation.org

The Parkinson Alliance
www.parkinsonalliance.org

Partners in Parkinson's
www.partnersinparkinsons.org



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.

PARKINSON.ORG
800.4PD.INFO (473.4636)
HELPLINE@PARKINSON.ORG



“We’re doing what

Michelle, Sharon and Nikki all have Parkinson’s disease. Here, they share the strategies that allow them to enjoy life to the fullest.

“Move as much as you can!”

Michelle Vajda
Cedar Grove, NJ
Diagnosed in 2018

Find new ways to work out

“I’ve started using resistance bands,” says Michelle, who is a longtime exercise enthusiast. Although she’s changed her workouts since her diagnosis, she regularly experiments to see what’s doable and what eases her symptoms. “At least twice a week, I go to the track, which is softer on my feet than the treadmill at the gym. I wrap the bands around my wrists and stretch while I walk. I’ll do eight laps around the track. For a long time, I couldn’t extend my arms and my hands are getting stiff, but this helps.”

Breathe

“Anxiety is a trigger for me,” says Michelle. “I get internal tremors [shaking sensations inside the body], pain and problems with balance and stiffness. It gets bad when I get upset or if I’m nervous or stressed. To calm down, I can take medication, but when I’m at work, I can be too busy to think about it so I just take a deep breath and work through it.”

Push through

During the “off times” when Michelle’s meds have no effect, her pain can last five hours, or all day!



PHOTO BY 4EYESPHOTOGRAPHY

She never knows, she says. “But I try to push myself. My doctor—a movement disorder specialist—tells me to keep moving as much as I can.” These days, she’s added spin class to her activities. “I can only stay on the bike 15 minutes and I’m the slowest one in the class, but it doesn’t matter. It’s all about movement and staying strong!”

Find workarounds

“For three years, I’ve been typing and using the calculator with only one hand,” says Michelle, who works full-time as a payroll analyst. “Vacuuming is difficult. Sometimes I can only do it for 20 minutes before I have to sit down. Then I’ll stand up

and try to do some more.” Getting dressed also requires patience—or flexibility. “Sometimes I can tuck in a shirt or button my pants—and sometimes I can’t. I’ll either fight with [a garment] until I get it, or I’ll wear something else.”

See your country

“I still travel, and every year I pick a place to go,” says Michelle, who enjoys solo trips. “It makes me feel independent. It makes me feel that I can do things on my own. I don’t have to rely on anyone. Since my diagnosis [in 2018], I’ve been to Denver and Portland, OR. When I’m at my destination, I take a car service everywhere and go on bus tours.”

we love!”

“Listen to your body!”

Sharon Krischer, Beverly Hills, CA, Twitchywoman.com, Diagnosed in 2009

Move your body

“If I don’t exercise, I can’t move,” says Sharon, who does some form of exercise five to six days a week. “I go to a boxing class for people with Parkinson’s disease twice a week. I do Vinyasa flow yoga two or three days a week. (The long holds in other styles of yoga are tough for me—I start to shake.) Once a week, I meet friends to play tennis. I’ve been playing with them 25 years. I have trigger finger and carpal tunnel syndrome, which have affected my game, but they won’t let me quit! I have a Peloton bike in my home gym—that’s my fallback. I’m part of a group on Facebook, Peloton4Parkinsons. I get on the bike—and it’s hard!” But the benefits, including easier movement and reduced fatigue, are worth it, she says.

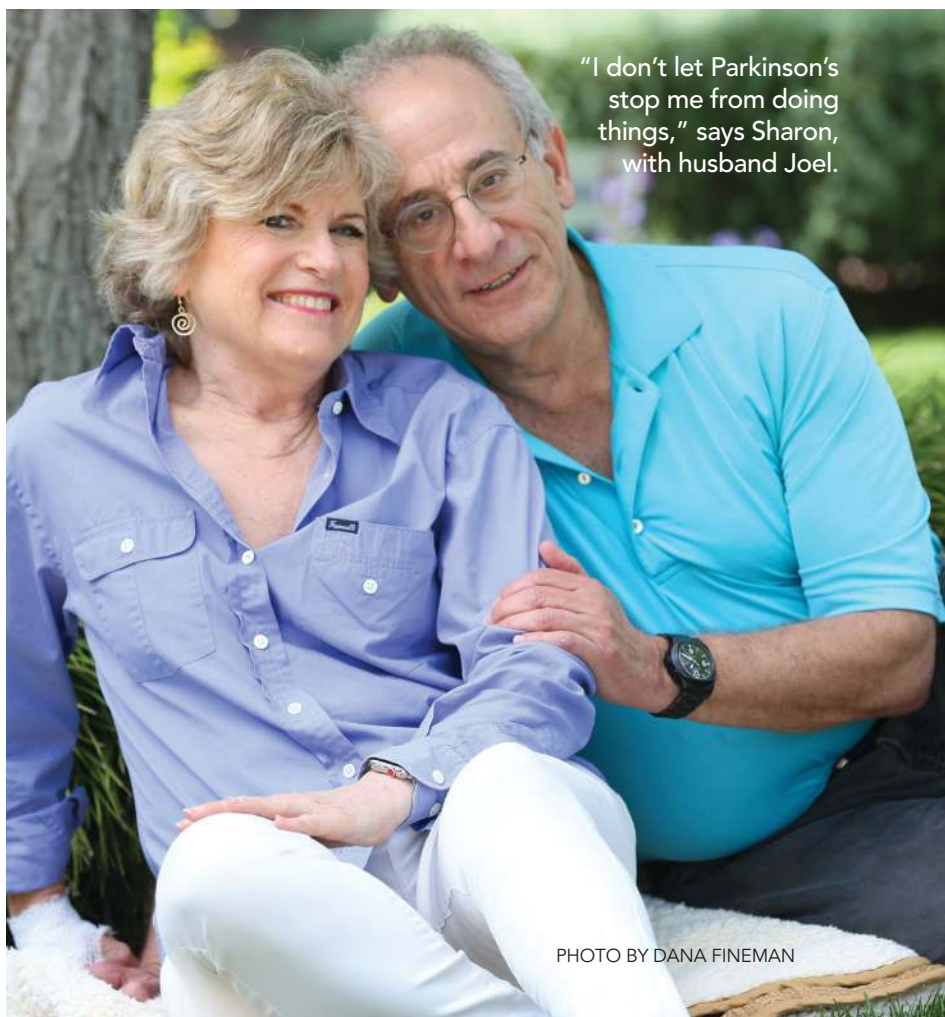
Find support in others with Parkinson’s

“I could do yoga at home, but I go to a class because I know people there and I talk with them. It gives you a baseline—you see how you’re doing. And if it’s yoga for Parkinson’s, you’re with people who understand what you’re dealing with. We become each other’s support system—we talk about everything! One man in my boxing class has a problem with freezing. He falls, we help him up. We’re there for him. I believe that’s why he keeps going to class—he’s got the support of others.”

Don’t give up the things you enjoy

“I don’t let Parkinson’s disease stop me from doing things,” says Sharon, who frequently travels around the world with her husband, Joel. “I’ve learned how to adapt. I take a sleeping pill on the plane and on the first night or two at my destination, which helps me get a good night’s sleep.” She also packs collapsible

walking sticks, which help her manage hilly areas and cobblestoned streets. “I don’t lift my foot enough. Walking sticks make my life easier. And they don’t look like a cane. They look like ski poles!” She adds: “There’s guaranteed to be one bad day on the trip.” When that happens, Joel goes sightseeing while Sharon rests. “I just listen to my body. It’s worth it!” ▶



“I don’t let Parkinson’s stop me from doing things,” says Sharon, with husband Joel.

PHOTO BY DANA FINEMAN

“Accept who you are”

Nikki Louisele

Charlevoix, MI

Justshakeitoff.com

Diagnosed in 2017

Let your attitude evolve

“Some days I feel like I’m kickin’ it, and some days I’m not,” says Nikki. “Yeah, I’m 46 now and it stinks [to have PD], but it isn’t the end. For me, I see it as an opportunity to use my voice to educate people, to meet new people and also to bring awareness to this disease. I think that accepting that this is who I am and not getting embarrassed when I stumble or drop something has helped. What I used to think was a horrible day is just a normal day now.”

Let go

“I’ve always been a bit of a type-A control freak, but I have had to release control,” says Nikki, who acknowledges that Parkinson’s symptoms sometimes foil her schedule. “I hate having to cancel plans, but I’m grateful to have amazing friends who keep reaching out and trying to plan get-togethers. They know I might have to cancel.”

Be the person you want your children to see

“I was angry and withdrawn after my diagnosis,” Nikki admits. “Then I thought, *This isn’t how I want my kids to handle adversity*. I needed to show them I’m stronger than this. So I’ve stopped apologizing for having Parkinson’s.

“I stumble every day. I can’t stay home every day!” says Nikki, with husband Mike.



PHOTO BY A13 STUDIOS

I stopped trying to hide my [shaking] hands. I know I’ve had people think I’m drunk. I get the side-eye from the person behind me in line at the store when I’m trying to put my credit card into the chip reader. I try to turn that into a teaching moment. I’ll look at them and go, ‘Damn Parkinson’s!’ It’s fairly new for me to own it.”

Live your life

“I tremor every day. I stumble every day. I spill things every day. I can’t stay home every day!” says Nikki. “Despite being tired or hurting, I’ve got to push through it. Having active teenagers forces me to do that. My daughter is a talented volleyball player. I just refuse to miss any of her games! I

love watching my kids do the things that they love!”

Consider therapy

“I started counseling three to four months after my diagnosis,” says Nikki. “I was really angry, really mad at the diagnosis. I was questioning God: *Why me? Why now?*” Nikki found a therapist who had experience working with people with Parkinson’s—someone she felt she could trust. “She encouraged me to write again, and sharing my journey and being able to say: *This is me. PD is not going away* has been a huge help in turning my attitude around. I’m done letting Parkinson’s rule me! I’m going to show Parkinson’s how I want to live my life!” 📧

Q&A

Answers to your most pressing questions about Parkinson's disease

MY HUSBAND SAYS I HAVE A BOYFRIEND!

Q What can I do about my husband? He has had Parkinson's disease for almost 22 years and has lately become paranoid. He accuses me of having a boyfriend (I don't), insists our son is stealing from us (he's not) and says there are strangers in our house (there aren't). I told him we need to tell his doctor, but he begs me not to. Can anything be done?

A Unfortunately, hallucinations and delusions are signs of Parkinson's disease (PD) psychosis, which many people with PD eventually develop. Not only can they greatly affect your husband's quality of life, but they also increase your burden. The good news is there are several interventions that can help control these symptoms, so I encourage you to discuss the situation with your husband's doctor. They may want to adjust your husband's Parkinson's medications and also rule out the presence of a metabolic problem or an infection that could be playing a role in these symptoms. Reducing other medications—such as powerful pain medications or muscle relaxants—that can affect memory and concentration is also critical. There are other medications that are additional options for treatment, including one that has recently been approved by the FDA for the treatment of PD psychosis.

ADDRESSING DEPRESSION

Q My sister was diagnosed with Parkinson's disease three years ago and seems depressed. When I

pointed that out, she said she's more concerned with treating the Parkinson's and says she'll "live with" the low moods. Is there any point to her getting treated for depression? Would it interfere with her treatment for PD?


A Depression and anxiety are among the most common "non-motor" symptoms in Parkinson's disease, present in more than half of patients at some point during the disease. Commonly, the initial strategy to manage depression in PD patients is to recommend counseling and exercise, in addition to maximizing and adjusting Parkinson's medications. If, however, your sister's symptoms are prolonged, or as soon as they start interfering with her quality of life, energy or motivation, she should discuss treating her depression with her doctor. Cognitive behavioral therapy may be helpful. Several medications are also an option—and, no, antidepressants do not interfere with medications for Parkinson's.

I'M SO TIRED

Q Is there anything that can help with this terrible fatigue? My neurologist tells me it's important to exercise, but I sometimes can't even get off the couch!

A For some people with Parkinson's disease, fatigue is one of the most disabling symptoms they experience. But it is manageable. First, your doctor can eliminate medications that may contribute to fatigue and rule out any other medical causes, such as low thyroid or anemia. They will also



want to manage other conditions you may have, such as depression or sleep apnea. But your doctor's advice is sound: Exercise has consistently shown benefits in reducing fatigue in people with PD. And while fatigue can make it hard to start exercising, physical activity may make you feel more energetic afterward. My suggestion: Start slow, and slowly increase the amount of exercise to avoid worsening your fatigue. Also, drink water regularly, start a consistent sleep schedule, take a short nap (10 to 30 minutes) early in the day, and stay socially connected! 

OUR EXPERT

Adolfo Ramirez-Zamora, MD



is associate professor of neurology and director of clinical trials at the University of Florida, Fixel Center for Neurological Diseases, a Parkinson's Foundation Center of Excellence.

Questions to ask your care team

Getting the answers to these questions can help you monitor your treatment and take charge of the next steps.



1. What do my symptoms tell you about my Parkinson's disease (PD)? Is it progressing?

2. Do you recommend a change to my treatment plan? If so, why?

3. What are the risks, benefits and side effects of this treatment?

4. How does PD and its treatment affect the health of my entire body?

5. Are there any lifestyle changes that could help me feel better?

6. Do I need to avoid any foods, supplements or over-the-counter medications?

7. Am I at risk for Parkinson's disease psychosis? How can I find out if I have it?

8. Are there any resources, such as a physical therapist, speech-language pathologist, dietitian or exercise class, that could help me?

9. Can you recommend a support group, either near my home or online?

10. Am I a candidate for a clinical trial to slow PD progression or to improve my symptoms?
