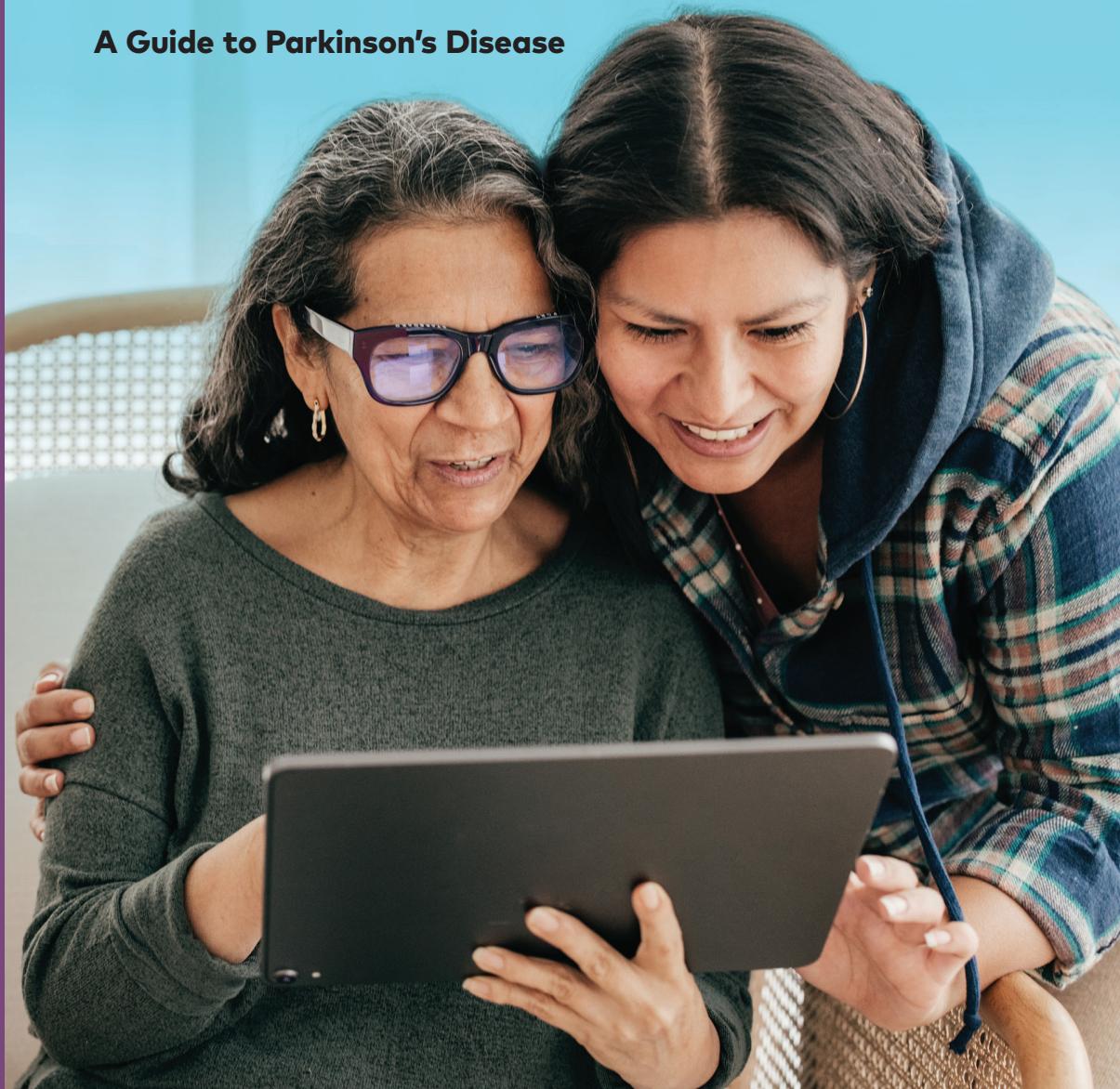


# Frequently Asked Questions

A Guide to Parkinson's Disease



## About This Book

This book is a practical guide about Parkinson's disease (PD), its symptoms, treatments, daily life and research. The information in this book is designed to help you understand the most frequently asked questions about PD. **It is not meant to replace the advice of expert medical professionals involved in your care.**

Throughout this book, we suggest keywords to search in our online PD Library to learn more about each topic. Visit [Parkinson.org/Library](https://Parkinson.org/Library) to discover related publications, videos, podcasts and more.

## Parkinson's Foundation Resources

Explore our books, fact sheets, webinars and podcasts in our PD library at [Parkinson.org/Library](https://Parkinson.org/Library).

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## Acknowledgments

This book has been made possible through generous Parkinson's Foundation donors.



Parkinson's disease (PD) affects everyone differently and changes over time. Learning about symptoms, treatment options and daily living strategies can help you navigate the challenges of living with PD and play an active role in your care.

This book answers some of the most frequently asked questions about Parkinson's. For more information, contact our Helpline specialists at **1-800-4PD-INFO (1-800-473-4636)** or **[Helpline@Parkinson.org](mailto:Helpline@Parkinson.org)**.

### **What kind of support does our Helpline offer?**

Staffed by nurses, social workers and health educators, the Parkinson's Foundation Helpline provides:

- Answers to PD questions.
- Referrals to health professionals and community resources.
- Educational materials, including publications, webinars and podcasts.

### **Who does the Helpline support?**

Our Helpline serves people with Parkinson's, families, care partners, health professionals and anyone seeking information about PD.

# Contents

## **Understanding Parkinson's** 4

Overview 4

What Happens in Parkinson's 7

Movement Symptoms & Complications 9

Non-movement Symptoms 13

## **Living with Parkinson's** 36

Finding Support 36

Staying Independent 37

The Family & Parkinson's 39





## Treating Parkinson's 24

Finding a Doctor 24

Medications & Surgical Treatments 25

Physical, Occupational & Speech Therapies 31

Exercise, Nutrition & Complementary Therapies 32

Hospital Safety 34

## Parkinson's Research: The Future 40

Drug Discovery & Development 40

Playing a Part in Research 42

Finding the Cure 44

Appendix: Medications List 45

Index 47



## CHAPTER ONE

# Understanding Parkinson's

### OVERVIEW

#### **What is Parkinson's disease?**

Parkinson's disease (PD) is a progressive neurodegenerative disorder that causes a gradual loss of brain cells that produce dopamine — a chemical necessary for movement. As dopamine decreases, movement becomes more difficult and slower.

Parkinson's is known as a movement disorder because of its more obvious symptoms: tremor, stiffness, slow movements and balance issues. However, non-movement symptoms, including trouble sleeping, depression and speech problems, are extremely common and can be just as challenging.

#### **How many people are currently living with Parkinson's?**

Nearly one million people in the U.S. and 10 million worldwide are living with PD. About 90,000 Americans are diagnosed with Parkinson's each year. It is the second most common neurodegenerative condition after Alzheimer's. Due to the growth in our aging population, the number of people with PD will increase substantially over the next 20 years.

## What is the average age of PD diagnosis?

People are diagnosed with Parkinson's at an average age of 60. About 4% of people are diagnosed before age 50. This is known as young-onset Parkinson's disease (YOPD).

To learn more about YOPD, visit [Parkinson.org/YOPD](https://Parkinson.org/YOPD).

## Can Parkinson's be cured?

No — not yet. However, many Parkinson's symptoms can be treated and researchers are making breakthroughs in understanding the disease, its causes and how to further improve therapies.

## How is Parkinson's diagnosed?

There is no single test for Parkinson's. A doctor makes a diagnosis based on a person's symptoms, medical history and a physical examination. Additional lab tests and imaging can sometimes help rule out other conditions.

To consider a diagnosis of Parkinson's disease, a person must have slow movements (bradykinesia) as well as one or more of the following:

- Stiffness or rigidity of the arms, legs, or trunk
- Shaking or tremor in a limb that occurs while it is at rest
- Balance issues

### NOTE

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**A PD diagnosis can take time. When symptoms first appear, many people speak to their family doctor, who may provide a referral to a neurologist if Parkinson's is suspected. Some neurologists have special training in diagnosing and treating PD and other movement disorders. This type of neurologist is called a movement disorder specialist.**

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Learn more about how to find a Parkinson's doctor on page 24.

## What is Parkinson's vs. parkinsonism?

Parkinsonism refers to a collection of movement symptoms associated with several conditions — including Parkinson's disease. These symptoms include slow movements (bradykinesia) along with stiffness,

## **6 FREQUENTLY ASKED QUESTIONS**

walking and balance issues and/or tremor. In addition to movement symptoms, parkinsonism disorders can share non-movement symptoms, such as mood and thinking changes, speech problems and sleep disturbances.

About 15% of all people with parkinsonism have an atypical variant, such as:

- Multiple system atrophy (MSA)
- Progressive supranuclear palsy (PSP)
- Corticobasal degeneration (CBD)
- Dementia with Lewy bodies (DLB)

These conditions are more serious and difficult to treat than PD.

Because there is no single test for parkinsonism disorders, and symptoms can overlap, a diagnosis can sometimes be unclear.

To learn more, search [understanding parkinsonism](#) or [atypical parkinsonism](#) at [Parkinson.org/Library](#).

### **How does Parkinson's progress?**

It is difficult to predict the course of Parkinson's for any individual. Each person experiences symptoms and progression differently. For some, symptoms change slowly, while for others, PD advances more rapidly.

Effective therapies are available to ease symptoms, prevent complications and help people live well at every stage of the disease.

Doctors often rely on rating scales to assess Parkinson's progression. The most commonly used rating scales focus on movement symptoms; newer scales also address non-movement symptoms.

### **PD PROGRESSION & SYMPTOMS**

- Early PD signs and symptoms can include changes in posture, small handwriting, constipation, sleep problems, soft voice, loss of smell and mood changes. Movement symptoms tend to occur primarily on one side and may not interfere with daily activities.
- In moderate or mid-stage PD, movement symptoms occur on both sides of the body. The body moves more slowly, and people may have more trouble with balance and coordination. "Freezing" episodes — when the feet feel stuck to the ground — may occur. PD medications

may "wear off" between doses and cause side effects, including dyskinesia (extra, involuntary movements).

- In advanced PD, a person may have problems with mobility and completing daily living activities without help. Thinking changes, specifically dementia, are also a hallmark of advanced PD.

## WHAT HAPPENS IN PARKINSON'S?

### How does the brain change in PD?

Dopamine is one of several chemical messengers brain cells use to communicate with the body — it is essential for movement. Dopamine-producing brain cells begin to die years before a PD diagnosis. As dopamine in the brain decreases, messages telling the body how and when to move are delivered abnormally, causing PD movement symptoms.

The loss of dopamine, along with changes in other brain networks, leads to non-motor symptoms, such as changes in mood, behavior, thinking and memory.

Researchers have discovered that Parkinson's is also linked to abnormal clumping of the protein alpha-synuclein, or Lewy bodies, in parts of the midbrain and brain stem, upper part of the nose and the gut.

### What causes Parkinson's?

Researchers believe a combination of genetic and environmental factors cause PD.

#### GENETIC FACTORS

Dozens of gene mutations have been linked to Parkinson's, though researchers are still uncovering what role they play in PD. Genetics cause about 10 to 15% of all PD. However, even when someone has a Parkinson's-associated gene mutation, the likelihood of developing the disease is low.

The Parkinson's Foundation offers genetic testing and counseling at no cost for those diagnosed with Parkinson's disease through its global genetics study. Enroll now at [Parkinson.org/PDGENEration](https://Parkinson.org/PDGENEration).

## **8 FREQUENTLY ASKED QUESTIONS**

Understanding the connection between PD and genetics can help us understand how the disease develops and ultimately how it can be treated or cured.

### **ENVIRONMENTAL FACTORS**

The extent to which environmental and genetics factors are involved in developing Parkinson's varies from person to person. The interactions can be quite complex.

A broad range of environmental exposures have been linked to PD including rural living, well water, manganese, pesticides and herbicides.

Some studies have demonstrated that prolonged exposure to certain chemicals is associated with higher PD risk. These include:

- Insecticides permethrin and beta-hexachlorocyclohexane
- Herbicides paraquat and 2,4-dichlorophenoxyacetic acid
- The fungicide maneb
- Trichloroethylene, a degreasing solvent found in dry cleaning

In 2009, the U.S. Department of Veterans Affairs added Parkinson's to a list of diseases possibly associated with exposure to Agent Orange.

Many people who are exposed to toxins never develop PD.

To learn more, search genetics or environmental at [Parkinson.org/Library](https://www.Parkinson.org/Library).

### **Can a bad fall, accident or shock cause Parkinson's disease?**

Many people with PD report that their symptoms first became noticeable after a severe shock, such as a head injury, medical crisis, surgery or severe emotional stress. Because Parkinson's brain changes develop over many years before symptoms appear, it is unlikely that any single event is the cause.

#### **NOTE**

**While there is no evidence that a mild head injury can lead to PD, traumatic brain injury — injury that results in amnesia or loss of consciousness — has been linked with an increased risk of developing Parkinson's years later.**

## What is drug-induced Parkinson's?

Drug-induced parkinsonism is a condition that mimics PD. It is caused by medications that block the chemical dopamine in the brain. These include drugs that treat nausea and vomiting, like metoclopramide (Reglan), and many antipsychotics, including haloperidol (Haldol).

If dopamine-blocking medications are stopped, symptoms usually go away over time. If a person who already has Parkinson's takes one of the drugs mentioned above, symptoms may worsen.

Because so many drugs impact the dopamine system, it is important to list all medications (including over-the-counter drugs and vitamins) when visiting your doctor.

## MOVEMENT (MOTOR) SYMPTOMS & COMPLICATIONS

### How does Parkinson's impact movement?

The following are the main PD movement symptoms. There are also secondary movement symptoms associated with Parkinson's.

#### SLOW MOVEMENTS (BRADYKINESIA)

Bradykinesia is a slowing of spontaneous and automatic movement. It must be present for a Parkinson's diagnosis. Signs of bradykinesia include slower walking, limited arm swing in one or both arms and decreased blinking or facial expression.

#### STIFFNESS (RIGIDITY)

Rigidity in Parkinson's is a stiffness in the arms or legs beyond what would result from normal aging or arthritis. Rigidity can occur on one or both sides of the body and affect movement. It can also cause discomfort and pain and may interfere with sleep.

#### RESTING TREMOR

In early Parkinson's, about 70% of people experience a slight tremor in the hand or foot on one side of the body, or less commonly in the jaw or face. Tremor often is noticed first in one finger. It usually appears when a person's muscles are relaxed, at rest, or when the arm hangs loosely. Some people can stop a hand tremor by keeping the hand in motion or in a flexed grip. Tremor often worsens with stress. As Parkinson's progresses, a tremor on one side of the body can extend to the other, but usually remains most noticeable on the side initially affected.

## 10 FREQUENTLY ASKED QUESTIONS

### BALANCE ISSUES (POSTURAL INSTABILITY)

A person with postural instability has difficulty balancing or trouble with falls, has lost some of the reflexes needed for maintaining an upright posture or may topple backwards if jostled even slightly.

To test for postural instability, the doctor gives a firm, backward tug on the standing individual's shoulders, observing how well balance can be regained. This is called the "pull test."

### SECONDARY MOVEMENT SYMPTOMS

In addition to the cardinal symptoms of Parkinson's, there are many other movement symptoms, including:

- Freezing, or a sensation of being stuck in place, often occurs when beginning to take a step, turning or walking through doorways.
- Small and crowded handwriting, called micrographia, caused by bradykinesia.
- Reduced facial expression, sometimes called facial masking or hypomimia, occurs as a result of bradykinesia and rigidity.
- Stooped posture, often noticed alongside short, shuffling steps, contributes to trouble with balance and walking.

To learn more, search [bradykinesia](#), [tremor](#), [freezing](#) or [posture](#) at [Parkinson.org/Library](#).

### Can stress worsen Parkinson's symptoms?

People with Parkinson's commonly report that acute stress worsens their movement symptoms, such as freezing, dyskinesia and tremor. They also report that chronic stress seems to worsen non-movement symptoms, particularly anxiety and depression.

To learn more, search [stress](#) at [Parkinson.org/Library](#).

### How can I prevent falls?

Parkinson's can make movement and balance more difficult, increasing the risk of falls — one of the most common and dangerous complications of PD. Falls can lead to fractures or head injuries.

Some people with Parkinson's have a tendency to sway backward when they stand or turn. Others hesitate or "freeze" when taking a first step through a narrow space, attempting to pivot or approaching a target, such as a chair.

Elevators, revolving doors and crowded situations can be especially challenging for people who experience freezing. PD-related fatigue and low blood pressure can also increase the risk of falling.

#### **SAFETY STRATEGIES**

Exercising early in PD, maintaining good posture and training to improve walking can minimize fall risks. For some, a simple medication change can reduce side effects or symptoms that increase fall risks. Canes and walkers can enhance safety for others.

For those who tend to sway backward, it is helpful to place feet in a firm stance and to use walls or counters for support. Certain situations may require help: an inclined driveway, a crowded space, icy or broken pavement or other obstacles. Avoid using stairs while carrying packages in both hands.

To learn more, search *falls* at [Parkinson.org/Library](https://Parkinson.org/Library).

#### **What is "wearing-off"?**

"Wearing-off" is when symptoms reappear in between Parkinson's medication doses. In early PD, medications can work so effectively that many people hardly notice their symptoms. But with time, the duration of benefit following each dose usually begins to shorten.

For some, wearing-off symptoms are an inconvenience that can be relieved by taking an extra dose of medication. For others, wearing-off symptoms are unpleasant and disabling. Wearing-off episodes may occur gradually and predictably, or they may happen suddenly and unexpectedly. People who experience them may develop a daily routine in which they cycle between "on" periods and "off" periods: when they are "on," their medications are working well and they are more mobile, but when they are "off," their medications have stopped providing relief, and they are stiffer and slower.

#### **MANAGING "OFF" TIME**

Treatment for "off" time is individualized. A typical approach is for the doctor to adjust medications while watching for new or increased medication side effects. Medication adjustments may include one or more of the following:

- Increasing or decreasing the frequency or dose size of your levodopa medication.

## 12 FREQUENTLY ASKED QUESTIONS

- Using extended-release, continuous or quick-acting dopaminergic medications.
- Adding medications to keep dopaminergic levels more consistent such as a COMT inhibitor, an MAO-B inhibitor, a dopamine agonist or istradefylline (an adenosine A2A antagonist).

In some people, these strategies may increase the likelihood of experiencing dyskinesia.

To learn more, search off at [Parkinson.org/Library](https://www.Parkinson.org/Library).

### What is dyskinesia?

Dyskinesia refers to involuntary, uncontrolled movements of the face, arms, legs or torso. It is a possible side effect of long-term use of levodopa, not a direct symptom of Parkinson's. These movements usually occur on the side of the body most affected by PD.

#### NOTE

**People who take carbidopa/levodopa may develop dyskinesia several years after starting treatment. In the later stages of PD, dyskinesia may appear more quickly when treatment begins due to changes in the brain's dopamine system. Other risk factors include being younger, having a lower body weight and being female.**

### MANAGING DYSKINESIA

Adjusting medications that impact dopamine or adding amantadine can often ease dyskinesia. For the right person, deep brain stimulation (DBS) may be very effective at reducing dyskinesia, and can be considered if medication adjustment is not successful. Researchers are currently looking at ways to reduce and prevent dyskinesia.

### Is pain a symptom of Parkinson's?

Pain is common in Parkinson's, but is often unrecognized by doctors. The causes of physical discomfort and pain include stiffness or rigidity, arthritis, tendonitis, aching caused by postural changes, dyskinesia and continuous or repetitive muscle contractions, known as dystonia. Some people with Parkinson's experience uncomfortable throbbing, burning or pulling sensations that occur when their medications wear off.

## ADDRESSING PAIN

It is often possible to identify the cause of pain through a careful description of symptoms and a thorough neurological examination. Depending on the cause, treatment may involve medication adjustments, physical therapy, anti-inflammatory drugs or other types of pain medication. For severe dystonia, injections of the muscle relaxant botulinum toxin may be effective. In some cases, deep brain stimulation (DBS) surgery may also help dystonia.

To learn more, search pain or dystonia at [Parkinson.org/Library](#).

## NON-MOVEMENT (NON-MOTOR) SYMPTOMS

### Are there symptoms not related to movement in Parkinson's?

Most people with PD also experience symptoms that do not involve movement and coordination, physical tasks or mobility. These "invisible" symptoms can often be more troublesome than movement symptoms.

Many researchers believe that non-movement symptoms may begin many years before diagnosis. The most common early symptoms include loss of sense of smell, constipation, small handwriting, mood changes and trouble sleeping. Having one or more of these symptoms does not necessarily mean someone will develop Parkinson's, but these markers are helping scientists to better understand how PD progresses.

This section will discuss the following symptoms:

- Sleep disorders
- Constipation
- Bladder issues
- Sexual dysfunction
- Speech and communication issues
- Saliva and dental problems
- Vision changes
- Postural low blood pressure
- Mood disorders

To learn more about non-movement symptoms and treatments, visit [Parkinson.org/Symptoms](#) or download our book *Medications: A Treatment Guide to Parkinson's Disease* at [Parkinson.org/Library](#).

## **Does Parkinson's cause sleep issues?**

Symptoms such as tremor, stiffness, limited mobility, bladder problems, dystonia and restlessness or anxiety can make it difficult for people with PD to sleep.

Some may experience rapid eye movement sleep behavior disorder (RBD): vivid dreams, which they physically act out without waking — sometimes falling out of bed or unintentionally hitting their bed partner. Scientists believe RBD may begin several years before diagnosis.

Other people may sleep too much during the day and then have insomnia at night, causing a "sleep-wake reversal" pattern. Another common issue involves falling asleep easily at bedtime, but waking in a few hours, unable to go back to sleep.

### **NOTE**

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**The importance of adequate sleep in Parkinson's cannot be overstated. Poor sleep can significantly worsen symptoms and reduce the effectiveness of medications. Excessive daytime sleepiness can make driving unsafe.**

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## **What can I do to improve sleep?**

When diagnosing sleep disorders, it is important to review potential causes, such as sleep apnea. Treatments for sleep disturbances typically aim to make a person more comfortable at night.

To improve sleep:

- Establish a regular bedtime routine.
- Schedule short naps earlier in the day, rather than in the evening.
- Minimize noise and light in the bedroom.
- Limit fluids after 6 p.m. to minimize nighttime urination.
- Avoid caffeine, chocolate, alcohol or other stimulants in the evening.

If "wearing-off" symptoms like stiffness and tremor interrupt sleep, your doctor might recommend an extra dose of carbidopa/levodopa late in the evening. Some people use controlled-release or extended-release carbidopa/levodopa at bedtime for this reason.

Medications to fall asleep or stay asleep at night (or stay awake during the day) can be effective. Some prescription medications, such as zolpidem (Ambien), can promote sleep but are associated with significant safety risks, and are not typically prescribed for people with PD. Sleep aids must be used with caution and with doctor supervision, especially in older adults, as getting up in the middle of the night while groggy may lead to falls.

To learn more, search [sleep](#) at [Parkinson.org/Library](#).

## Why is constipation a problem for people with Parkinson's?

Parkinson's can affect the autonomic nervous system, which is responsible for regulating smooth muscle activity of the gut. If this system is not working properly, the intestinal tract may slow down, causing constipation. Certain medications may also cause or contribute to constipation. Other causes include:

- Not drinking enough water
- Too little fiber
- Lack of exercise
- Resisting the urge to have a bowel movement
- Weakness of the pelvic floor muscles
- Iron supplements, opioid pain medication, antacids containing calcium or aluminum, certain antidepressants and blood pressure medications

### EASING CONSTIPATION

The first step to addressing constipation is to increase fiber and fluids. Stool softeners are also useful. Medications may be prescribed.

Laxatives can be helpful but should first be discussed with a doctor.

To learn more, search [constipation](#) at [Parkinson.org/Library](#).

## Can Parkinson's cause bladder problems?

Bladder problems are more common as people age — whether they have PD or not. In addition, Parkinson's can impact the nerves and muscles that control the bladder. The most common issues are an urgent need to urinate and frequent urination, especially at night. These issues can occur even when the bladder is not full.

## **16 FREQUENTLY ASKED QUESTIONS**

Bladder issues can be caused by conditions not related to Parkinson's.

- For men, an enlarged prostate can make it difficult to fully empty the bladder.
- For women, a weak pelvic floor, urinary tract infection or hormonal changes can contribute to bladder problems.

### **BOOSTING BLADDER CONTROL**

Many people can improve bladder control by limiting caffeinated beverages, scheduling regular bathroom visits and exercising the pelvic floor. Several medications are available to treat urinary problems, but some can cause confusion and other bothersome side effects, so it is important to discuss options with your healthcare team. Protective garments can help keep skin healthy and dry and prevent accidents.

*To learn more, search [urinary](#) or [bladder](#) at [Parkinson.org/Library](#).*

### **Are sexual problems common for people with Parkinson's?**

People with PD can enjoy fulfilling sexual relationships. However, Parkinson's can cause challenges. Men may experience difficulty with erections. Women may have vaginal dryness or find it more difficult to reach orgasm. For both men and women, PD symptoms such as tremor, stiffness, depression, anxiety or bladder issues can impact sex drive.

### **DISCUSS SEXUAL CHALLENGES**

It is important to talk about any issues with your healthcare team. There are therapies available to work through sexual challenges. For example, there are medications that can improve erectile dysfunction. Testosterone therapy may increase sex drive in women and men.

### **NOTE**

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**Medications that impact dopamine can cause hypersexuality — especially dopamine agonists. This problem can have a serious impact on people with PD and their care partners and should be promptly reported to the healthcare team so medications can be adjusted.**

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*To learn more, search [intimacy](#) or [sexuality](#) at [Parkinson.org/Library](#).*

## Does Parkinson's cause speech problems?

Speech and voice changes are often the earliest signs of Parkinson's, but not everyone with PD will have the same issues. Common difficulties include speaking softly, using a monotone voice, slurring words, mumbling and stuttering. For some, thinking changes can make it harder to find the right word, focus on conversations or get a sentence started. Sometimes limited facial expression can cause miscommunication. Learn how speech therapy can help on pages 31-32.

To learn more, visit [Parkinson.org/Speech](https://Parkinson.org/Speech).

## How does Parkinson's affect saliva?

Excess saliva in people with Parkinson's does not result from increased saliva production — rather, a decrease in spontaneous swallowing and slower movements of the tongue, mouth and throat muscles that help clear saliva. Stooped posture can cause excess saliva to slip out of the mouth, which can lead to drooling.

### TREATMENT OPTIONS

A speech therapist (also called a speech-language pathologist) can perform a swallow test to diagnose any swallowing and drooling problems and provide strategies to help.

Sucking on hard candy or chewing gum (preferably sugarless) can activate the jaw and stimulate swallowing. A sweatband worn on the wrist can be used to wipe the mouth.

Adjusting PD medications may make it easier to swallow.

Severe drooling can be treated with salivary gland injections with botulinum toxin.

To learn more, visit [Parkinson.org/Drooling](https://Parkinson.org/Drooling).

## Does Parkinson's affect dental health?

Saliva production is reduced in PD. This can lead to tooth decay or cavities. Movement symptoms such as tremor or stiffness may also make brushing and flossing more difficult. If this is the case, an electric toothbrush can make brushing easier.

Dyskinesia, mobility issues, tremor and swallowing difficulties can make dental visits more challenging.

### **STRATEGIC TIMING FOR DENTAL VISITS**

Try to schedule early morning appointments 60 to 90 minutes after your first dose of PD medication to have your best "on" time. Also, wait times tend to be shorter earlier in the day.

To learn more, search dental at [Parkinson.org/Library](#).

### **Are vision changes part of Parkinson's?**

Similar to other movement symptoms caused by loss of dopamine, some vision issues are related to changes in eyeball movement. Some people may notice blurry vision or experience dry eyes.

It may be helpful to see a neuro-ophthalmologist. These specialists are trained in diagnosing and treating vision problems associated with PD and other neurological diseases.

To learn more, search vision at [Parkinson.org/Library](#).

### **Why do people with Parkinson's need to pay attention to low blood pressure?**

Postural low blood pressure, also called orthostatic hypotension (OH), is a sharp drop in blood pressure that happens when a person rises after lying down or sitting. When OH is related to a nervous system disease, such as Parkinson's, it is also called neurogenic orthostatic hypotension (nOH). This common PD symptom can cause dizziness or fainting and put people at risk for falls or injury.

Some medications, including those used for treating Parkinson's, can affect blood pressure.

#### **NOTE**

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**To check for OH, your doctor should take three blood pressure readings: laying down, within 1 minute after standing and after standing for 3 minutes.**

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### **NAVIGATING LOW BLOOD PRESSURE**

To reduce risks, it is important to change positions slowly, drink enough water (six 8-ounce glasses) and discuss medications that may lower blood pressure with your doctor.

There are several medications that can help reduce OH symptoms, such as fludrocortisone, midodrine and droxidopa. Your doctor may recommend adding salt to your diet.

To learn more, search [blood pressure](#) or [orthostatic hypotension](#) at [Parkinson.org/Library](#).

## **Are depression and anxiety caused by Parkinson's?**

In addition to everyday life stressors and the emotions of coping with a PD diagnosis, Parkinson's itself decreases brain chemicals that impact mood. Parkinson's Foundation research found that mood symptoms, such as depression and anxiety, can impact the health of people with PD more than movement symptoms.

### **Along with "feeling blue," depression symptoms can include:**

- Insomnia or excessive sleeping
- Reduced energy
- Loss of interest or pleasure in normal activities
- Reduced ability to concentrate
- Difficulty engaging with others
- Sexual dysfunction
- Loss or gain of appetite and weight
- Feelings of guilt and self-pity
- Thoughts of death or suicide

### **Symptoms of anxiety may include:**

- Feelings of unease
- Jitteriness
- Worry or panic
- Difficulty breathing or swallowing
- Heart fluttering
- Shaking
- Cold sweats

Feelings of anxiety can be related to movement symptoms. For example, tremor or freezing resulting from an "off" episode might cause anxiety or embarrassment — especially if it occurs around others; this anxiety can worsen symptoms, creating a vicious cycle.

### **MANAGING DEPRESSION & ANXIETY**

Diet, exercise, good sleep, practicing mindfulness and maintaining daily routines can improve mood symptoms. Cognitive behavioral therapy (CBT) is an effective type of psychotherapy that focuses on changing thought patterns and behavior related to depression and anxiety. Often the most successful approach to supporting mental health is a personalized one that includes a combination of medication, counseling or psychotherapy, exercise, lifestyle changes and support.

*To learn more, search [depression](#), [anxiety](#) or [mood](#) at [Parkinson.org/Library](#).*

### **What is apathy and why can it occur in Parkinson's?**

Apathy is a lack of interest in things or activities that are normally pleasurable. Similar to PD movement symptoms, apathy may result from a loss of dopamine in the brain. It can develop at any stage — even before diagnosis.

### **MANAGING APATHY**

Currently, there are no proven treatments for apathy. However, maintaining a regular routine, continuing to exercise, taking medications on time every time and avoiding isolation can all help manage apathy. Family and friends and regular participation in a support group can help with staying engaged and motivated.

People with apathy are encouraged to meet with their doctor to:

- Evaluate and optimize PD medications — better movement may reduce apathy.
- Get tested for depression and apathy — standard rating scales can identify the cause of mood changes and point to the right treatment.
- Discuss ways to get the most restful sleep possible — sleep difficulties contribute to fatigue.
- Explore other treatment options — there are no approved medications to treat apathy, but some people may benefit from cholinesterase inhibitors (medicines that block the breakdown of the enzyme acetylcholine, such as rivastigmine, etc.), stimulants or certain types of antidepressants.

*To learn more, search [apathy](#) or [mood](#) at [Parkinson.org/Library](#).*

## Is dementia part of Parkinson's?

Nearly all people with PD will experience some degree of thinking (cognitive) changes. Some will eventually develop more significant cognitive changes that impact their ability to carry out daily tasks and live independently. This is known as dementia.

Parkinson's disease dementia (PDD) can cause problems focusing, multitasking, problem solving and interpreting spatial information, which can impact driving. PDD is different than Alzheimer's disease. For example:

- People with Alzheimer's have language difficulties earlier than people with PDD and do not form new memories.
- People with PDD have more ability to compensate and to remember information and events with cues.

### NOTE

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**Depression can sometimes mimic dementia symptoms, so it is important to screen for depression and seek treatment if needed.**

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### MANAGING DEMENTIA

Thinking changes can have a major impact on quality of life and should be discussed with a doctor, preferably a neurologist.

There are many non-drug strategies to improve quality of life for people with PDD, such as:

- Cognitive training to strengthen thinking.
- Behavior intervention to establish routines and adapt the home.
- Games and activities that include a person's strengths and interests.
- Social engagement through support groups, memory cafes and creative arts programs designed for people with dementia.

For some people, reducing Parkinson's medications can help improve mental clarity. People experiencing PD-related dementia may benefit from medications used to treat Alzheimer's symptoms such as rivastigmine, donepezil and galantamine.

**NOTE**

**Delirium is a sudden and serious change in mental abilities that can look like dementia but is often caused by something else, like an infection or a medication side effect. Symptoms should be reported to the doctor right away. Most of the time, these symptoms are treatable and may be reversible.**

To learn more, search cognition or dementia at [Parkinson.org/Library](https://www.Parkinson.org/Library).

**Do people with Parkinson's experience hallucinations or delusions?**

Yes. Healthcare professionals refer to these symptoms as Parkinson's disease psychosis. It is important to the well-being of people with PD and care partners to identify hallucinations as early as possible and take steps to reduce them.

**DELUSIONS**

A delusion is a set conviction that something is real when it is not. For example, a person may believe a partner is being unfaithful, that someone is trying to deceive or harm them or suspect a song or television show is speaking to them directly. Delusions can have a big impact on the person experiencing them and their loved ones, and may cause feelings of embarrassment, fear, suspicion or jealousy.

**ADDRESSING PD PSYCHOSIS**

In Parkinson's, hallucinations and delusions can stem from a combination of factors. They can be related to changes in the brain caused by the disease itself, medication side effects and other health conditions. Addressing these symptoms begins with talking to the healthcare team, who should follow a series of steps to figure out the best course of treatment.

1. **Assessment** begins with reviewing symptoms, prior history, disease stage and available support systems.
2. **Treatment** generally starts with reducing or stopping medications that might be related to these symptoms, often in a specific order.
3. **An antipsychotic medication may be prescribed** if further symptom relief is needed.

Many antipsychotic medications can worsen movement symptoms and should not be prescribed for people with PD. Some of these medications, such as haloperidol (Haldol), are commonly prescribed in the hospital setting for people who are agitated or anxious. The medications used to treat Parkinson's psychosis (hallucinations and delusions) are clozapine, quetiapine and pimavanserin.

To learn more, search hallucinations, delusions or psychosis at [Parkinson.org/Library](https://www.Parkinson.org/Library).

### **What causes compulsive behaviors like gambling and shopping, and should I worry about them?**

Some people with PD will develop compulsive behaviors while receiving dopamine therapy. Known as impulse control disorders (ICDs), these behaviors may include compulsive gambling, shopping, hoarding or hypersexuality.

These behaviors usually result from dopamine agonists but have also been linked to many medications for PD movement symptoms. It is important to immediately alert your Parkinson's doctor if behavior changes of this type occur. Some medications may need to be reduced or replaced with an alternative.

To learn more, search impulse control at [Parkinson.org/Library](https://www.Parkinson.org/Library).

**CHAPTER TWO**

# Treating Parkinson's

## FINDING A DOCTOR

### **How can I find a doctor who knows how to manage and treat Parkinson's?**

Treating Parkinson's disease (PD) requires a team approach involving not only the person living with PD, but also family members, the primary care doctor, a neurologist and other healthcare professionals.

When symptoms first appear, many people choose to speak to their primary care doctor, who may provide a referral to a neurologist if Parkinson's is suspected. Some neurologists, called movement disorder specialists, have additional training in diagnosing and treating Parkinson's and other movement disorders.

People who cannot find a movement disorders specialist in their area may benefit from traveling once or twice a year for an appointment. During the rest of the year, a local neurologist with Parkinson's experience can work together with the specialist to coordinate care.

When looking for doctors with Parkinson's knowledge, talk to other people with PD, discuss options with your primary care doctor or contact the Parkinson's Foundation Helpline at **1-800-4PD-INFO (1-800-473-4636)** or **Helpline@Parkinson.org**.



## How often should I see my Parkinson's doctor?

Most people should plan to see their Parkinson's doctor at least every six months, especially if they are taking PD medications. If you are experiencing new symptoms or side effects, more frequent visits may be needed.

## What other specialists do I need on my healthcare team?

A person's symptoms and needs change over the course of Parkinson's. Building a "healthcare team" that includes different types of experts to address symptoms on an as-needed basis is important.

In addition to your primary care doctor and a neurologist, such as a movement disorders specialist, your healthcare team may consist of other healthcare professionals, including a physical and/or occupational therapist, speech therapist, nutritionist, gastrointestinal doctor, social worker, mental health specialists and others.

Some people with PD may find all of these professionals in one practice or center, but many will have to explore their community's resources.

Ask your doctor to provide recommendations and referrals.

### NOTE

**Collaboration among members of the healthcare team helps ensure all aspects of care are addressed, including medication management, therapies and supportive services.**

## MEDICATIONS & SURGICAL TREATMENTS

### What are the treatment options for Parkinson's?

Parkinson's symptoms are different from person to person. Treatment should be tailored to an individual's unique needs. Researchers continue to focus on developing treatments to slow or reverse progression, but in the meantime, the goal of treatment is to improve movement and relieve symptoms with as few side effects as possible.

Medications are part of an overall treatment strategy, which can include exercise, rehabilitation therapies (physical, occupational and speech), and surgery.

## **What medications are currently available to treat Parkinson's?**

There are many effective prescription medications for Parkinson's symptoms. It is common for people to take a variety of medications — at different doses and times of the day — to manage symptoms.

In the chapter we will discuss:

- Levodopa
- Dopamine agonists
- COMT (catechol-O-methyl transferase) inhibitors
- MAO-B (monoamine oxidase-B) inhibitors
- Adenosine A2A Antagonists
- Amantadine
- Anticholinergics

Most Parkinson's medications work by replacing, mimicking or boosting dopamine, the brain chemical that plays an important role in mood, movement and motivation. Dopamine drugs are associated with potential side effects, including nausea, drowsiness, low blood pressure, hallucinations, dyskinesia and compulsive behaviors.

The choice of medication and dose is often influenced by symptoms, side effects and how well it helps them continue doing what they love. Medications work best when they are taken on a regular schedule and combined with exercise, good nutrition and adequate sleep.

### **LEVODOPA**

Developed in the 1960s, levodopa remains the most potent medication for Parkinson's. By itself, levodopa produces nausea and vomiting. Most levodopa medications are combined with carbidopa to minimize this side effect.

Levodopa comes in different forms and strengths. Some forms work quickly (immediate release) and need to be taken more often, while others release the medication more slowly over time (controlled or extended release). There are options that deliver the medication more continuously or can be used for unexpected, sudden "off" episodes. There is also a combined formulation that includes the COMT inhibitor entacapone.

**NOTE**

**Keep track of which type of levodopa medication you take. The accidental substitution of a different form or strength may increase your symptoms or side effects.**

**Levodopa side effects may include, but are not limited to, the following:**

- Nausea and stomach upset
- Dizziness
- Dyskinesia
- Headache
- Low blood pressure
- Sleepiness
- Behavioral changes (impulsiveness)
- Hallucinations (seeing things that are not there)

**Reducing Side Effects**

Initiating treatment with a low starting dose and slowly increasing it can minimize side effects. This is particularly helpful in elderly people who can be more sensitive to new medications. People who experience nausea may need to take carbidopa/levodopa with food, although this may lessen its effectiveness. For persistent nausea or vomiting, adding extra carbidopa to each dose of carbidopa/levodopa can also help. You can find information about other levodopa side effects throughout the book.

- Dyskinesia - page 12
- Dizziness and low blood pressure - pages 18-29
- Hallucinations - pages 22-23

**DOPAMINE AGONISTS**

Unlike levodopa, which converts into dopamine in the brain, dopamine agonists mimic the effect of dopamine. They can be used in early PD on their own, or later in combination with carbidopa/levodopa.

Dopamine agonists are available in quick and long-acting versions. There is also a patch form, as well as a quick-acting, injectable rescue medication.

## **28 FREQUENTLY ASKED QUESTIONS**

Compared to levodopa, dopamine agonists generally provide less benefit for movement symptoms, but they are longer acting, which may help reduce "off" time and improve levodopa benefits.

Many dopamine agonist side effects are similar to those of carbidopa/levodopa, but dopamine agonist use is less likely to cause or contribute to dyskinesia.

### **What to Watch For**

Impulse control disorders, which involve behaviors such as uncontrolled gambling, increased sexual urges (hypersexuality) and excessive eating and shopping, commonly occur as a result of dopamine agonist therapy.

These disorders may also lead to a type of compulsive, repetitive activity, called punding. Punding can include excessive organizing, sorting or collecting items.

### **NOTE**

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**The person experiencing impulse control issues may not notice changes themselves, so care partners are key to recognizing these behaviors and alerting the doctor.**

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### **COMT INHIBITORS**

Catechol-O-methyltransferase (COMT) is an enzyme that deactivates levodopa in the bloodstream before it gets to the brain. COMT inhibitors block this enzyme, so more levodopa is available to get into the brain. This can increase levodopa benefits and reduce "off" time. COMT inhibitors generally have minimal side effects, though they may intensify some levodopa-related side effects, particularly dyskinesia.

### **MAO-B INHIBITORS**

Monoamine oxidase-B (MAO-B) is an enzyme that breaks down dopamine. An MAO-B inhibitor blocks that chemical breakdown, increasing available dopamine. MAO-B inhibitors can be useful on their own to modestly improve PD movement symptoms, or may be used as an add-on to other medications, such as levodopa.

### **What to Watch For**

Potential side effects include mild nausea, dry mouth, lightheadedness

and constipation. When MAO-B inhibitors are prescribed, pharmacists warn people about interactions with other drugs, especially antidepressants. These types of reactions are very rare. If you are taking an MAO-B inhibitor, review potential new medications for possible interactions with your doctor.

#### **ADENOSINE A2A ANTAGONIST**

Istradefylline is an adenosine A2A receptor antagonist used in combination with carbidopa/levodopa to manage "off" time in Parkinson's. Although it does not boost or increase dopamine, it can contribute to dyskinesia in some people.

#### **AMANTADINE**

Amantadine is used to treat Parkinson's movement symptoms and is sometimes prescribed on its own in early stages of PD when symptoms are mild. It is more commonly used to reduce dyskinesia. Its path through the brain is not fully known, but it likely impacts multiple neurotransmitters (chemical messengers) — including dopamine and glutamate — to achieve its benefits.

The most frequent side effects of amantadine are nausea, dry mouth, lightheadedness, insomnia, confusion, swollen feet and hallucinations.

#### **ANTICHOLINERGICS**

Anticholinergics can be helpful for tremor and may ease dystonia. They do not act directly on the dopaminergic system. Instead, they decrease the activity of acetylcholine, a chemical that regulates movement.

Side effects can include blurred vision, dry mouth, constipation and urinary retention. **Anticholinergic medications must be used with care. They can cause significant side effects, particularly in older adults, and should not be used by people older than 70.**

To learn more, search medication at [Parkinson.org/Library](https://Parkinson.org/Library).

#### **What Parkinson's drug is most often prescribed first?**

Some experts advocate early treatment with levodopa because it is the most effective drug for treating PD symptoms. Others may choose to prescribe dopamine agonists, which are not as potent as levodopa but are less likely to lead to movement fluctuations and dyskinesia, two long-term complications of levodopa therapy.

## **What is deep brain stimulation?**

Deep brain stimulation (DBS) is a powerful surgical therapy that has been used successfully in tens of thousands of people to address movement symptoms, certain medication side effects and some non-movement symptoms. While it is the most important therapeutic advancement since the development of levodopa, DBS is not for every person with Parkinson's. It is most effective — sometimes dramatically so — for people who experience disabling tremors, bothersome rigidity (stiffness), wearing-off episodes or medication-induced dyskinesia.

During DBS surgery, electrodes are inserted into a targeted area of the brain using MRI (magnetic resonance imaging) and other tools. DBS can be directed to different parts of the brain — including the subthalamic nucleus, globus pallidus internus and thalamus — crucial regions for mobility and tremor control. The choice of target depends upon a person's symptoms and goals.

### **DBS PROCEDURE**

A device called an implantable pulse generator or IPG (similar to a pacemaker) is inserted below the collarbone to provide a continuous electrical current to a part of the brain involved in movement. After the surgery, the person returns to the medical center at regular intervals for programming of the implanted device. Individuals can check the battery or turn the device on or off using either a mobile app or a handheld controller. An IPG battery lasts for several years or more and is relatively easy to replace under local anesthesia.

### **EFFECTS OF DBS**

While DBS can greatly decrease some Parkinson's symptoms, minimize wearing off and often allows a person to reduce their medications (which may improve dyskinesia), it is not a cure.

### **NOTE**

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**Generally, symptoms that improve with levodopa therapy will also improve with DBS but in a smoother, more continuous way. Tremor is an exception to this rule. Even if tremor fails to improve with levodopa therapy, it often improves with DBS.**

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In contrast, DBS can worsen speech — even if speech improves with levodopa therapy.

DBS does not typically address symptoms that do not respond to carbidopa/levodopa such as balance, talking and thinking issues.

#### **WHO IS A CANDIDATE FOR DBS?**

An ideal DBS candidate is someone whose symptoms respond well to levodopa but who experiences wearing-off episodes or dyskinesia that impacts quality of life. The person must be in good general health. DBS is typically not recommended for people whose symptoms respond poorly to levodopa, or for those with severe cognitive or emotional difficulties.

Surgery is best performed at a center with established DBS expertise. The ideal center is one that has neurosurgeons trained in DBS surgery and a dedicated healthcare team available for screening, post-operative care and deep brain stimulator programming. A person considering DBS surgery should be well-informed about the procedures and have realistic expectations. An effective support system of family or friends is essential to help cope with the emotional and physical demands of the surgery.

To learn more, visit [Parkinson.org/Surgery](https://Parkinson.org/Surgery).

## **PHYSICAL, OCCUPATIONAL & SPEECH THERAPIES**

### **How can speech, physical and occupational therapy help PD?**

**PHYSICAL THERAPY** helps people keep moving. A physical therapist can suggest exercises and strategies that target specific movement challenges. Physical therapists with knowledge about PD can teach techniques to prevent and recover from freezing episodes.

**OCCUPATIONAL THERAPY** helps people navigate work and home environments safely and maintain greater levels of independence. An occupational therapist can also offer ways to overcome PD-related living challenges, such as difficulty eating or dressing.

**SPEECH THERAPY**, also called speech-language pathology, helps people with voice and speech issues, often the earliest signs of PD. A speech therapist also addresses language and swallowing difficulties. Speech

therapists with specialized training in Parkinson's help people speak and swallow with more awareness.

To learn more, search physical therapy, occupational therapy, speech or swallowing at [Parkinson.org/Library](https://www.Parkinson.org/Library).

## **Are there Parkinson's-specific movement and speech programs?**

Yes, there are several.

- The Parkinson Wellness Recovery PWR!Moves exercise program, [pwr4life.org](https://pwr4life.org)
- Lee Silverman Voice Treatment (LSVT) BIG, a movement-based program and LSVT LOUD speech-based therapy, [lsvtglobal.com](https://lsvtglobal.com)
- The Parkinson Voice Project SPEAK OUT! speech and swallowing therapy, [parkinsonvoiceproject.org](https://parkinsonvoiceproject.org)

The Parkinson's Foundation Helpline at **1-800-4PD-INFO (1-800-473-4636)** or [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org) can help you find an experienced physical, occupational or speech therapist near you trained to work with people with PD.

## **EXERCISE, NUTRITION & COMPLEMENTARY THERAPIES**

### **How does exercise benefit Parkinson's?**

Exercise is an important part of healthy living for everyone. For people with PD, exercise is more than healthy — it is a vital component to maintaining balance, mobility and everyday living activities. Research shows that exercise and physical activity can not only maintain and improve mobility, flexibility and balance but also ease non-movement PD symptoms such as depression or constipation.

Parkinson's Foundation research shows that people with PD who start exercising earlier in their disease course for a minimum of 2.5 hours per week experience a slowed decline in quality of life compared to those who start later. Establishing early exercise habits is essential to overall disease management.

## **EXERCISE TYPES**

To help manage the symptoms of PD, an exercise program should include these key components:

- Aerobic activity
- Strength training
- Balance, agility and multitasking
- Flexibility

These elements are included in many types of exercise: Biking, running, tai chi, yoga, Pilates, dance, weight training, non-contact boxing, qigong and more all have positive effects on PD symptoms.

## **NOTE**

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**There is no specific "exercise prescription" for Parkinson's. The best exercise depends on your specific symptoms and challenges. If you are just getting started, low-intensity exercise, such as walking, can help you ease into a routine. If safe, this can be increased to regular, more vigorous activity. The goal is to be consistent.**

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To learn more, search exercise or fitness at [Parkinson.org/Library](https://Parkinson.org/Library).

## **Do people with Parkinson's need to follow a special diet?**

While there is no PD-specific diet, one including a variety of whole grains, vegetables, fruits and protein-rich foods can improve health. The right foods can help improve medication effects, keep bones strong, maintain general health and fight constipation and weight loss.

### **TIPS FOR ADDRESSING DIET CHALLENGES**

**Challenge:** Taking levodopa close to a protein-rich meal — such as meat, fish, eggs, dairy, nuts or beans — may interfere with its absorption, causing the drug to work more slowly or less effectively.

**Solution:** Taking levodopa up to an hour before mealtime on an empty stomach or with a dry cracker or toast can maximize effectiveness.

**Challenge:** Parkinson's can cause the gut to slow down.

**Solution:** Eating fiber-rich fruits and vegetables, drinking plenty of fluids and exercising regularly can help manage constipation.

**Challenge:** Swallowing issues are common in Parkinson and can lead to undesired weight loss.

**Solution:** Talk to a doctor, who can provide a thorough medical evaluation, about progressive weight loss that has no clear cause. Request a referral to a speech therapist for difficulty swallowing.

*For more information, search [nutrition](#) at [Parkinson.org/Library](#).*

### **Do vitamins or supplements help treat Parkinson's?**

Sometimes levodopa therapy can lead to low B vitamin levels. Usually, a one-a-day multivitamin with folic acid, B12, and B6 is enough to address this issue. Vitamin levels should be checked regularly in PD. Your doctor can recommend additional supplements if needed.

### **What is mindfulness and how can it support Parkinson's?**

Mindfulness is a practice of bringing awareness to your thoughts, feelings, senses and environment. Research shows that mindfulness benefits mental, emotional and physical wellbeing in PD. Mindfulness is a tool that helps manage stress, ease symptoms of depression and anxiety and improves movement symptoms. There are many ways to practice mindfulness, including meditation, breathing exercises and movement.

*To learn more about mindfulness, register for our weekly Mindfulness Mondays program or view past videos. Visit [Parkinson.org/PDHealth](#).*

### **Do acupuncture and massage therapy have a role in treating PD?**

There is no scientific evidence that acupuncture or massage therapy have any effect on Parkinson's itself. However, people with PD report these therapies can temporarily provide relief from aching muscles, reduce stress, promote relaxation and lessen some symptoms.

## **HOSPITAL SAFETY**

### **Do I need to prepare for a planned or unexpected hospital stay?**

People with Parkinson's are at a higher risk of hospitalization and face many challenges while in the hospital, including worsening symptoms. This year alone, one in every six people with PD will experience avoidable complications in the hospital. Symptoms, such as confusion or thinking changes, may develop due to stress, infection, fatigue, sleep issues, surgery or new medications.

Careful preparation and clear communication can help minimize complications and recovery time.

- Order and download the free Hospital Safety Guide at [Parkinson.org/HospitalSafety](https://Parkinson.org/HospitalSafety).
- Carry Parkinson's identification in case of an emergency.
- Prepare a hospital "go bag" using the information in the Hospital Safety Guide and keep it by the door.
- Choose a hospital care partner to accompany you in the hospital.
- Plan to communicate the urgency of your PD needs, including medications on time, every time.

**Use the Five Parkinson's Care Needs** to communicate your PD needs during a hospital visit.



**Need 1:** I need my hospital chart to include my exact medications and match my at-home schedule.



**Need 2:** I need to take my Parkinson's medications within 15 minutes of my usual schedule.



**Need 3:** I need to avoid medications that make my Parkinson's worse. These medications include those that block dopamine, sedatives and certain pain medications.



**Need 4:** I need to move my body as safely and regularly as possible, ideally three times a day.



**Need 5:** I need to be screened for swallowing changes to safely maintain my medication routine and minimize my risk of aspiration pneumonia and weight loss.



## CHAPTER THREE

# Living with Parkinson's

### FINDING SUPPORT

Living with the challenges of Parkinson' disease (PD) usually requires a team approach. Look to your closest connections — people who are invested in the outcome of what you are doing — for emotional support. Connect with others also living with PD, whether in person or online, to unite with people that understand your journey on a personal level. Looking for inspiration? Read stories written by people living with Parkinson's at [Parkinson.org/MyPDStory](https://Parkinson.org/MyPDStory).

### How can I find a local support group?

Support groups can provide a place to share similar experiences and tips for living with Parkinson's. Some groups provide general support, while others focus on special populations, such as those people living with young onset PD or care partners. Support groups may provide educational programs and organize members to raise awareness in local communities.

The Parkinson's Foundation Helpline can provide referrals to nearby groups. Contact us at **1-800-4PD-INFO (1-800-473-4636)** or [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org). If a group is not available in your community, consider a virtual support group.

## STAYING INDEPENDENT

### What kind of assistive devices and adaptive strategies are available for people with Parkinson's?

There are special utensils and devices that can make eating and other daily activities easier. Some furnishings, such as a shower chair, can be helpful in the bathroom. Voice amplifiers may help improve communication.

A walking aid, like a cane or walker, can help people with balance problems avoid falls by providing support and encouraging careful steps. Some walkers have a laser light to help guide steps if freezing occurs. For more severe balance issues, a wheelchair or motorized scooter might be needed. A prescription may be required for insurance coverage of certain devices.

A physical or occupational therapist can help identify the best assistive devices and adaptive strategies for your specific needs, and teach you how to use them safely. Learn more on pages 31-32.

To learn more, visit [Parkinson.org/Assistive](http://Parkinson.org/Assistive).

### Is there financial assistance for people with Parkinson's?

There are programs that can help offset some of the financial difficulties associated with Parkinson's — such as the costs of medical equipment and medications.

- **Area Agencies on Aging:** 1-800-677-1116; [eldercare.acl.gov](http://eldercare.acl.gov)

Local Area Agencies on Aging link seniors and adults with disabilities to financial aid and programs designed to support their safety and independence.

Local programs might offer case management, care partner assistance, care coordination, healthcare referrals, food stamp and energy bill savings applications, home-delivered meals, health insurance counseling, low-cost senior housing referrals and more.

- **Veteran Benefits:** 1-800-827-1000; [benefits.va.gov/benefits](http://benefits.va.gov/benefits)

There are several organizations that offer small grants for people with PD to meet a specific need (typically medical equipment, exercise class fees, supplies, or medical care).

There are also several organizations that offer medications co-pay assistance to qualifying individuals.

To learn more, contact our Helpline at **1-800-4PD-INFO** (**1-800-473-4636**) or [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org).

### **Is it safe to drive with Parkinson's?**

The ability to drive depends on a person's specific symptoms, as well as the presence of other age-related changes. People with PD must take extra caution as they may have slowed reaction times, difficulty processing visual and spatial information or problems with judgment.

People with unpredictable wearing-off episodes may find themselves suddenly unable to move behind the wheel. Others may become sleepy while driving due to medication effects or sleep deprivation. A fender bender, or a tendency to veer across lanes or around corners, calls into question a person's ability to judge distances accurately.

#### **NOTE**

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**If you or family members are worried about your driving, it is time to assess the situation. Your doctor may suggest a driving evaluation — available through your local DMV. Sometimes training can improve driving skills if issues are minor.**

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Call the Association for Driver Rehabilitation Specialists at 1-866-672-9466 or ask the doctor for a referral.

To learn more, search [driving](#) at [Parkinson.org/Library](#).

### **Should people with Parkinson's drink alcohol?**

In many cases, moderate alcohol consumption is fine for people with Parkinson's. However, alcohol can worsen symptoms or interact with medications, so it is important to talk to your doctor first.

## THE FAMILY & PARKINSON'S

### What role can family members play?

Family members and care partners play an important role in PD. They can provide support and feedback, assist with household tasks — such as paying bills or attending doctor appointments — or aid in personal care tasks, such as helping a loved one dress or shower.

It is important for family members to recognize the sometimes unpredictable nature of Parkinson's. By staying alert and offering help when it is needed, family members can find the right balance between helping the person with PD and encouraging independence.

### THE IMPORTANCE OF EMOTIONAL SUPPORT

Some people with PD experience mood symptoms that can interfere with staying active and engaged. Talking to family and friends or joining a support group can help. Your doctor can also recommend treatment.

Often, a combination of support, medications and psychotherapy or counseling is the most successful approach.

The Parkinson's Foundation provides educational events and materials for care partners. In addition, many community support groups either include care partners and family members or may have a separate group available.

To learn more, visit [Parkinson.org/Caregiving](http://Parkinson.org/Caregiving) or [Parkinson.org/PDHealth](http://Parkinson.org/PDHealth).

### Are there resources to support care partners?

Several organizations provide education and resources to care partners and loved ones of people with PD:

- The Caregiver Action Network, the Family Caregiver Alliance and the Well Spouse Association, support care partners to people living with various diseases, including Parkinson's.
- Area Agencies on Aging provide care partner support and resources. Use the Eldercare Locator at [www.eldercare.acl.gov](http://www.eldercare.acl.gov) or 1-800-677-1116 to find the closest.
- Care partners of veterans can also call the U.S. Department of Veterans Affairs Caregiver Support Line at 1-855-260-3274.

**CHAPTER FOUR**

# Parkinson's Research: The Future

**DRUG DISCOVERY & DEVELOPMENT****Are there any new drugs on the horizon for Parkinson's?**

Research into breakthrough treatments for Parkinson's is an essential part of the fight against this disease. Several promising new drug therapies are "in the pipeline" of discovery or development. New surgical approaches and gene therapies are also currently being tested. In addition, an increased understanding of PD genetics is moving us closer to "precision medicine" — treatments that can be tailored based on a person's unique genes.

To learn more, search [new medications](#) at [Parkinson.org/Library](#).

**Why does it take so long for a new drug to become available?**

While a cure for Parkinson's can't come fast enough, safety is a top priority in advancing new treatment. The route from the laboratory to the medicine cabinet is complex.

The U.S. Food and Drug Administration (FDA) carefully oversees the development, testing, labeling and marketing of all pharmaceutical products. Medication development starts in a laboratory. If a compound appears promising, it undergoes rigorous testing to determine safety and effectiveness.

**The Research Process** begins with development of a new compound in the lab, continues with the three phases of clinical research, and concludes with approval by the US Food and Drug Administration



Clinical trials can only begin once a new medication passes all animal safety tests. The drug's effectiveness is then measured in carefully designed, large-scale trials involving hundreds of people.

### NOTE

In some clinical trials, participants are randomly assigned to receive either the medication being tested or a placebo (an inactive substance that looks like the test drug) to evaluate the treatment's effectiveness. A double-blind study — in which neither the researcher nor the participant knows who receives the active medication until the end — ensures an unbiased evaluation.

Sometimes, the FDA requires more extensive drug testing than the manufacturer anticipated, which can delay the process by years.

Search for clinical trials at [Clinicaltrials.gov](https://www.clinicaltrials.gov).

### What does "neuroprotection" mean?

Neuroprotection describes treatment that may slow down, stop or reverse the progression of a brain disease by preventing brain cells from being lost, repairing them or encouraging new ones to grow. There is growing evidence that exercise — particularly high-intensity exercise — is neuroprotective and may slow the progression of PD symptoms.

For more information, visit [Parkinson.org/Exercise](https://www.Parkinson.org/Exercise).

## PLAYING A PART IN RESEARCH

### Should I consider participating in a clinical research study?

Despite promising research, there is neither a cure for Parkinson's nor medications that can reverse its course. But there can be. Medications currently used for treating PD are available only because other people volunteered to help researchers develop them.

**Clinical research in Parkinson's** takes many forms. Drug trials are designed to test new treatments and require participants to follow a careful protocol and make several visits to the study center.

**New surgical technique trials for PD** are more complex, with extensive pre-operative screening and testing, as well as long term follow-up.

**Other research, such as genetic studies**, may only require one visit for researchers to collect information and obtain a blood sample.

All types of research allow the discovery of new ideas and information and advance our understanding of Parkinson's.

### NOTE

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**In most trials, medical care and study medication is provided to participants for free. People who participate in clinical research tend to receive closer attention and more frequent evaluations than people with Parkinson's in routine clinical practice.**

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### EVALUATING RISK

Talk to your doctors about the possible benefits or risks of a trial and ensure that trial coordinators answer all your questions before making a decision to participate in research.

All trials in the U.S. must be approved by an Institutional Review Board (IRB) — a committee of physicians, statisticians, researchers, advocates and others — before recruiting participants. FDA protocol, research ethics and careful monitoring by the IRB protects clinical research participants from harm, ensures an ethical trial and safeguards the medical information of participants.

If you are interested in participating in research, ask your PD doctor for study recommendations and visit [Parkinson.org/JoinaStudy](https://Parkinson.org/JoinaStudy).

To learn more, search *research* or *clinical study* at [Parkinson.org/Library](https://Parkinson.org/Library).

## Are there other ways to get involved in Parkinson's research?

**Advocating for Parkinson's research** is as important as participating in trials. This might include educating the Parkinson's community about clinical studies, working to improve development of new therapies or advocating on a local or national level for Parkinson's research funding.

The Parkinson's Foundation Research Advocates program equips people with Parkinson's and care partners with the knowledge and skills necessary to pair up with scientists and health professionals. This strong, nationwide network prioritizes research, improves studies and brings together the people who live with Parkinson's and those developing new treatments.

Research advocates complete in-person or virtual training to understand the science of Parkinson's and new treatment developments. Research advocates continue to grow their advocacy knowledge and connections through continuing education opportunities and tools provided by the Foundation.

To learn more, contact [PatientEngagement@Parkinson.org](mailto:PatientEngagement@Parkinson.org).

**Brain donation** after death is critical to advancing Parkinson's research. Donations give scientists an opportunity to better understand PD and other neurodegenerative disorders. Brain research provides insights on improving treatments and medications. People with PD (and sometimes those without) can choose to donate their brains to Parkinson's research.

However, deciding to be a brain donor can be difficult. For those who decide to make a donation, it is important to talk to family, make a living will and enroll with an organization in advance. There are several programs that accept donations from people with Parkinson's — each with their own requirements.

Contact the Parkinson's Foundation Helpline at **1-800-4PD-INFO** (**1-800-473-4636**) or [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org) for more information about organizations that accept brain donations.

## FINDING A CURE

### What are the future strategies for finding better treatments and a cure for PD?

Parkinson's is a complex disease — there is still a lot we don't know. Comprehensive research is key to unlocking its causes, developing life-changing treatments and discovering a cure. The Parkinson's Foundation invests hundreds of millions of dollars in innovative science to spur discovery and improve the lives of the 10 million people living with Parkinson's worldwide.

We drive steady progress in the fight for a cure, funding some of the world's best and brightest researchers and sharing our findings across the Parkinson's community — from people with Parkinson's and their loved ones, to healthcare professionals and researchers.

Fostering open access to scientific discoveries sparks innovation, allowing researchers from all backgrounds to identify the fastest lanes to new therapies.

*For more information, visit [Parkinson.org/Cure](https://Parkinson.org/Cure).*

## Appendix: FDA-Approved Medications for PD

Visit [Parkinson.org/Medications](https://Parkinson.org/Medications) and [Parkinson.org/Symptoms](https://Parkinson.org/Symptoms) or download our book *Medications: A Treatment Guide to Parkinson's Disease* to learn more about these medications and other medications used off-label\* for Parkinson's symptoms.

### CLASS/TYPE MEDICATION

#### MEDICATIONS FOR MOVEMENT SYMPTOMS

<b>Levodopa</b>	Carbidopa/levodopa (Sinemet, Dhivy) Carbidopa/levodopa controlled release Carbidopa/levodopa/entacapone (Stalevo) Carbidopa/levodopa extended release (Crexont, Rytary) Carbidopa/levodopa enteral suspension (Duopa) Foscarbidopa/foslevodopa (Vyalev) for subcutaneous infusion Levodopa inhalation powder (Inbrija)
<b>Dopamine Agonists</b>	Apomorphine injection (Apokyn) Pramipexole (Mirapex, Mirapex ER) Ropinirole, Ropinirole extended release Rotigotine transdermal patch (Neupro)
<b>COMT Inhibitors</b>	Entacapone (Comtan) Opicapone (Ongentys) Tolcapone (Tasmar)
<b>MAO-B Inhibitors</b>	Rasagiline (Azilect) Safinamide (Xadago) Selegiline (L-deprenyl, Eldepryl) Selegiline oral disintegrating (Zelapar)
<b>Adenosine A2A Antagonist</b>	Istradefylline (Nourianz)
<b>Amantadine</b>	Amantadine (Symmetrel) Amantadine extended release (Gocovri, Osmolex ER)
<b>Anticholinergics</b>	Benztropine (Cogentin) Trihexyphenidyl HCL (formerly Artane)

\*Off-label commonly refers to medication prescribed for a condition or symptom for which it has not received FDA approval.

## Appendix: FDA-Approved Medications for PD

Visit [Parkinson.org/Medications](https://Parkinson.org/Medications) and [Parkinson.org/Symptoms](https://Parkinson.org/Symptoms) or download our book *Medications: A Treatment Guide to Parkinson's Disease* to learn more about these medications and other medications used off-label\* for Parkinson's symptoms.

USE	MEDICATION
<b>MEDICATIONS FOR NON-MOVEMENT SYMPTOMS</b>	
Nausea	Carbidopa (Lodosyn)
Low Blood Pressure	Droxidopa (Northera)
Psychosis	Pimavanserin (Nuplazid)
Dementia	Rivastigmine (Exelon)

### MEDICATIONS FOR NON-MOVEMENT SYMPTOMS

Nausea	Carbidopa (Lodosyn)
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# Index

- Acupuncture 34
- Adenosine A2A Antagonist 12, 26, 29, 45
- Alcohol Use 14, 38
- Amantadine 12, 15, 26, 29, 45
- Antipsychotic Medication 9, 22-23
- Anxiety 19-20, 34
- Apathy 20
- Anticholinergics 26, 29, 45
- Assistive Devices 37
- Bladder Problems 13, 15-16
- Bradykinesia (*See Slow Movements*)
- Brain Changes 7-8, 22
- Brain Donation 43
- Carbidopa/levodopa 12, 14, 26-27, 45
- Causes 7-8
- Clinical Trials 41-42
- Compulsive behaviors 23, 28
- COMT Inhibitors 12, 26, 28, 45
- Constipation 13, 15
- Deep brain stimulation (DBS) 30-31
- Delusions 22-23
- Depression 19-21
- Dental health 13, 17-18
- Diagnosis 5-7
- Diet (*See Nutrition*)
- Dopamine Agonists 12, 16, 23, 26-29, 45
- Driving 14, 21, 38
- Drooling (*See Saliva*)
- Exercise 32-33, 41
- Financial Assistance 37-38
- Falls 8, 10-11, 37

- Finding a Doctor **24**
- Hallucinations **22-23**
- Hospital Safety **34-35**
- Impulse Control Disorders (ICDs) **23, 28**
- Low Blood Pressure **13, 18-19, 46**
- MAO-B Inhibitors **12, 26, 28-29, 45**
- Massage **34**
- Medications for Movement Symptoms **26-29, 45**
- Medications for Non-Movement Symptoms **14-23, 46**
- Mindfulness **34**
- Movement Disorders Specialist **24-25**
- Nutrition **33-34**
- Occupational Therapy **31-32, 37**
- Orthostatic Hypotension (**See Low Blood Pressure**)
- Pain **12-13**
- Parkinsonism **6-7**
- Physical Therapy **31-32, 37**
- Progression **6-7**
- Psychosis **22-23, 46**
- Research **40-44**
- Rigidity (**See Stiffness**)
- Saliva **13, 17**
- Sexual Problems **13, 16**
- Slow Movements **9**
- Speech Therapy **31-32**
- Speech Issues **13, 17**
- Stiffness **9**
- Stress **10**
- Support Groups **36**
- Surgery **25, 30-31, 34**
- Tremor **9**
- Urinary Problems (**See Bladder Problems**)
- Vitamins **34**
- Wearing "Off" **11-12**

## About the Parkinson's Foundation

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. Information about Parkinson's and resources are available at [Parkinson.org](https://Parkinson.org).

## Your generosity makes this publication possible.

The Parkinson's Foundation is proud to provide this guide and other educational materials at no cost to people around the world. If you found this resource helpful, please consider a donation to help us continue to offer up-to-date, high quality educational materials about Parkinson's, as well as fund innovative research and support services.

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[Parkinson.org/Volunteer](https://Parkinson.org/Volunteer)

#### Mail:

Parkinson's Foundation  
5757 Waterford District Dr.  
Suite 310  
Miami, FL 33126

#### Phone:

1-800-4PD-INFO  
(1-800-473-4636)

#### Scan QR Code:



# THANK YOU FOR YOUR SUPPORT!



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