

# Frequently Asked Questions

**A Guide to Parkinson's Disease**



**PARKINSON'S FOUNDATION RESOURCES**

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**People affected by Parkinson's disease (PD) — those living with Parkinson's, their family members, their friends and the healthcare professionals that care for them — are all looking for answers to questions about the disease, its symptoms and treatments. This booklet is a compilation of the most frequently asked questions that the Parkinson's Foundation receives through its Helpline. Some of these questions have simple answers, while others have complicated answers that are still evolving.**

While each question is answered as comprehensively as possible, it is important to note that Parkinson's is truly an individualized disease. Each person's experience with Parkinson's, including its symptoms and the rate at which it progresses, is different. Not all people living with Parkinson's will experience all of the symptoms and side effects discussed in this booklet. Rather, each person may find that certain symptoms are more troublesome and may experience these symptoms at different points in the disease.

*If you have additional questions that you would like to discuss, please call our Helpline at 800-4PD-INFO or email us at [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org).*

# Contents

## Understanding Parkinson's 5

- Overview 5
- What Happens in Parkinson's? 8
- Motor Symptoms & Complications 11
- Non-motor Symptoms 18

## Living with Parkinson's 39

- Finding Support 39
- Staying Independent 40
- The Family & Parkinson's 42





## Treating Parkinson's 27

Finding a Doctor 27

Medications & Surgical Treatments 28

Complementary & Alternative Therapies 35

Exercise & Nutrition 37



## Parkinson's Research: The Future 44

Drug Discovery & Development 44

Playing a Part in Research 46

Finding the Cure 48



## CHAPTER ONE

# Understanding Parkinson's

### OVERVIEW

#### What is Parkinson's Disease?

Parkinson's disease (PD) is a chronic and progressive movement disorder that involves the malfunction and death of vital nerve cells in the brain, called neurons. Some of these dying neurons produce dopamine, a chemical that sends messages to the part of the brain that controls movement and coordination. As PD progresses, the amount of dopamine produced in the brain decreases, leaving a person unable to control movement normally.

Parkinson's was originally described in 1817 by James Parkinson in his *Essay on the Shaking Palsy*. It is not considered a fatal disease and the way it progresses is different for each person.

Primary motor signs of Parkinson's disease include tremor, slowness, rigidity and postural instability. Most people with Parkinson's also experience non-motor symptoms that may precede motor symptoms — and a PD diagnosis — by years. The most recognizable early symptoms include loss of sense of smell, constipation, mood and sleep disorders, and neurogenic orthostatic hypotension (low blood pressure when standing up).

*Learn more about symptoms on page 11.*

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

Worldwide, there are more than 10 million people living with Parkinson's disease. In the United States (US), as many as one million people live with Parkinson's, which is more than the combined number of people with multiple sclerosis, muscular dystrophy and ALS. Approximately 60,000 Americans are diagnosed with PD each year. This number does not reflect the thousands of cases that go undetected.

## What is the average age of PD diagnosis?

The average age at which someone is diagnosed is 60. Incidence of PD increases with age, but an estimated four percent of people with PD are diagnosed before the age of 50. This is referred to as young-onset PD. Although symptoms are similar, people with young-onset PD often face different financial, family and employment concerns.

## Can Parkinson's be cured?

The answer is no — not yet. However, many symptoms of Parkinson's disease can be treated and researchers are making advances in understanding the disease, its causes and how to best treat it.

## What is Parkinson's versus parkinsonism?

Because there are no definitive diagnostic tests for Parkinson's, the diagnosis can sometimes be unclear. The term "parkinsonism" is a generic descriptive term that refers to the whole category of neurological diseases that causes slowness of movement. This category includes the classic form of Parkinson's disease, many atypical variants, sometimes called "Parkinson's Plus Syndromes," and any other brain disease that resembles Parkinson's, such as normal pressure hydrocephalus, vascular parkinsonism or drug-induced parkinsonism. In all cases of parkinsonism, there is a disturbance in the dopamine systems of the basal ganglia — a part of the brain that controls movement. This dopamine deficiency leads to the characteristic combination of tremor, slowness, rigidity and postural instability.

Classic (idiopathic) Parkinson's is the most common and most treatable form of parkinsonism. For a significant minority, about 15 percent of all persons with parkinsonism, one of the atypical variants may be present. These conditions are more serious and less treatable than classic PD, and include multiple system atrophy (MSA), progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and Lewy Body Dementia.

*For more information, visit [Parkinson.org/Library](http://Parkinson.org/Library) or call 800-4PD-INFO.*



## How is Parkinson's diagnosed?

Often, the diagnosis of Parkinson's is first made by an internist or family physician. Many people seek an additional opinion from a neurologist with experience and specific training in the assessment and treatment of PD — referred to as a movement disorder specialist.

To diagnose Parkinson's, the physician takes a careful neurological history and performs an examination. Although there are no standard diagnostic tests for Parkinson's, DaTscan, an imaging technology, may provide beneficial insights to help a doctor confirm a PD diagnosis in the early stages of the disease. The main role of any additional testing is to exclude other diseases that imitate Parkinson's disease, such as stroke or hydrocephalus.

Very mild cases of PD can be difficult to confirm, even by an experienced neurologist. This is in part because there are many neurological conditions that mimic the appearance of Parkinson's.

The Parkinson's Foundation recommends that a person with symptoms resembling those of PD consider making an appointment with a movement disorder specialist.

*Learn more about how to find a Parkinson's specialist on page 28.*

## What are the stages of Parkinson's?

The stages of Parkinson's correspond both to the severity of movement symptoms and to how much the disease affects a person's daily activities. At all stages of Parkinson's, effective therapies are available to ease symptoms and make it possible for people with PD to live well.

With mild Parkinson's, movement symptoms, often tremor, occur on one side and may be inconvenient, but do not affect daily activities. Friends may notice changes in a person's posture, walking ability or facial expression. Regular exercise improves and maintains mobility, flexibility, range of motion and balance, and also reduces depression and constipation.

With moderate Parkinson's, movement symptoms occur on both sides of the body. The body moves more slowly and trouble with balance and coordination may develop. "Freezing" episodes — when the feet feel stuck to the ground — may occur. Parkinson's medications may "wear off" between doses and may cause side effects, including dyskinesias (involuntary movements). Regular exercise, perhaps with physical therapy, continues to be important for good mobility, and balance and occupational therapy may provide strategies for maintaining independence.

## 8 FREQUENTLY ASKED QUESTIONS

With advanced Parkinson's, a person may have great difficulty walking; may be in a wheelchair or bed most of the day. The person is not able to live alone and will need assistance with all daily activities. Cognitive problems may be prominent, including hallucinations and delusions. Balancing the benefits of medications with their side effects becomes more challenging.

### How quickly does Parkinson's progress?

Each person with Parkinson's experiences the disease differently. Some people experience tremor as their primary problem while others may instead suffer from frequent falls, muscle rigidity or slowness of movement. Some people with Parkinson's have a very stable course with little progression over many years while others develop disability earlier in the disease. Physicians cannot accurately predict the course of Parkinson's for any individual, and must instead focus on reducing a person's symptoms, preventing complications and improving his or her quality of life.

There are rating scales that a physician may use to understand PD progression. The most commonly used rating scales are focused on the motor symptoms but new scales include information on non-motor symptoms (such as problems with sense of smell).

## WHAT HAPPENS IN PARKINSON'S?

### What happens to brain cells in Parkinson's?

Parkinson's disease occurs when a group of cells in the area of the brain called the substantia nigra begin to malfunction and die. These cells produce a chemical called dopamine. Dopamine is a neurotransmitter, or chemical messenger, that sends information to the parts of the brain that control movement and coordination.

When a person has Parkinson's, the dopamine-producing cells begin to degenerate and the amount of dopamine produced in the brain decreases. Messages from the brain telling the body how and when to move are delivered abnormally, leaving a person incapable of initiating and controlling movements in a normal way. For most people, this process leads to the characteristic motor symptoms of Parkinson's: tremor, slowness, rigidity and postural instability.

Scientists are also exploring the idea that loss of cells in other areas of the brain and body contribute to Parkinson's. For example, researchers have discovered that the hallmark sign of Parkinson's disease — clumps of a protein alpha-synuclein, which are also called Lewy bodies — are found not only in the mid-brain but also in the brain stem and the olfactory bulb. These areas of

the brain correlate to non-motor functions such as sense of smell and sleep regulation. The presence of Lewy bodies in these areas could explain the non-motor symptoms experienced by some people with PD before any motor sign of the disease appears. The intestines also have dopamine cells that degenerate in Parkinson's, and this may be important in the gastrointestinal symptoms that are part of the disease.

## What causes Parkinson's disease?

To date, despite decades of intensive study, the causes of Parkinson's remain unknown. Many experts think that the disease is caused by a combination of genetic and environmental factors, which may vary from person to person.

Scientists have identified aging as an important risk factor; there is a two to four percent risk for PD among people over age 60, compared with one to two percent in the general population.

### GENETIC FACTORS

The vast majority of Parkinson's cases are not directly inherited. About 15 to 25 percent of people with Parkinson's report having a relative with the disease. In large population studies, researchers have found that people with an affected parent or sibling have about twice the risk of developing PD compared to someone without an affected relative. However, even with a positive family history, the risk of developing PD is less than 10 percent.

Researchers have discovered several gene mutations that can cause the disease directly, but these affect only a small number of families. Some of these mutations involve genes that play a role in dopamine cell functions. Parkinson's has developed at an early age in individuals with mutations in genes for parkin, PINK1, LRRK2, DJ-1, and glucocerebrosidase, among others. However, genetic testing is not currently recommended as part of the evaluation of a person with PD.

Because genetic forms of a disease can be studied in great detail in the laboratory, and because understanding the rare genetic forms of Parkinson's may help us to understand more common forms of the disease, genetics is currently the subject of intense research.

### **For more information:**

*Listen to our Substantial Matters Podcast #7: Genetics as a Guide to Neuroprotection in Parkinson's Disease at [Parkinson.org/Podcast](http://Parkinson.org/Podcast).*

*Download our fact sheet "Genetics and Parkinson's Disease: What have we learned?" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

### ENVIRONMENTAL FACTORS

Some scientists have suggested that Parkinson's disease may result from exposure to an environmental toxin or injury. Epidemiological research has identified several factors that may be linked to Parkinson's, including rural living, well water, manganese and pesticides.

Some studies have demonstrated that prolonged occupational exposure to certain chemicals is associated with an elevated risk of PD. These include the insecticides permethrin and beta-hexachlorocyclohexane (beta-HCH), the herbicides paraquat and 2,4-dichlorophenoxyacetic acid and the fungicide maneb. In 2009, the US Department of Veterans Affairs added Parkinson's to a list of diseases possibly associated with exposure to Agent Orange. A synthetic neurotoxin agent called MPTP can also cause immediate and permanent parkinsonism. The compound was discovered in the 1980s in individuals who injected themselves with a synthetic form of heroin contaminated with MPTP. Cases of MPTP-induced Parkinson's in the general population are exceedingly rare.

It is noted that a simple exposure to an environmental toxin is never enough to cause Parkinson's. Most people exposed to a toxin do not develop the disease. In fact, there is no conclusive evidence that any environmental factor, alone, can be considered a cause of the disease. However, environmental factors have been helpful in studying laboratory models of Parkinson's. Scientists continue to pursue these clues to understand why Parkinson's disease occurs.

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

Many people with Parkinson's report that their symptoms first became apparent after a severe shock, such as a head injury, a medical illness, a surgical operation or severe emotional stress. Because Parkinson's is a slow degeneration of brain cells that occurs over many years before symptoms appear, it seems unlikely that any single event causes the disease. There is no convincing evidence that a mild head injury can lead to Parkinson's. Traumatic brain injury — injury that results in amnesia or loss of consciousness — has been associated with an increased risk of developing PD years after the injury. The syndrome of parkinsonism and dementia that occurs in some boxers is the result of hundreds of blows to the head over many years.

For a person who associates the onset of Parkinson's with a fall, head injury or an extreme stressor, the likely explanation is that this individual already had mild, unrecognized Parkinson's that became more evident in response to the stressor.

## MOTOR SYMPTOMS & COMPLICATIONS

### What is drug-induced Parkinson's? Is it permanent or reversible?

Drug-induced parkinsonism is a condition that mimics Parkinson's. It is caused by drugs that block the effects of dopamine in the brain. A person experiencing drug-induced Parkinson's will have symptoms — resting tremor, rigidity, slowness of movement, problems with balance and others — that may be clinically indistinguishable from classic Parkinson's.

Drugs that can cause parkinsonism include neuroleptic tranquilizers, sometimes used to control hallucinations or agitation, or to induce sleep. Examples of this class of drugs include chlorpromazine (Thorazine®), haloperidol (Haldol®), fluphenazine (Prolixin®), pimozide (Orap®), risperidone (Risperdal®), aripiprazole (Abilify®) and olanzapine (ZYPREXA®). Drugs for nausea such as metoclopramide (Reglan®) and prochlorperazine (Compazine®) can also block dopamine in the brain and cause parkinsonism. Tetrabenazine (Xenazine®), a drug used to treat certain movement disorders, can deplete brain dopamine and cause parkinsonism. Certain cardiac medications, including amiodarone (Cordarone®) and calcium channel blockers, may induce parkinsonism.

When these drugs are stopped, the dopamine system returns to normal and usually all of the features of parkinsonism reverse. If a person who already has Parkinson's disease takes one of the drugs mentioned above, the PD symptoms may worsen.

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

### What are the motor signs of Parkinson's?

The diagnosis of Parkinson's does not come from a test, but instead requires a careful medical history and a physical examination to detect the cardinal signs of the disease, including:

#### RESTING TREMOR

In the early stages of the disease, about 70 percent 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. A typical onset is tremor in one finger. The tremor consists of a shaking or oscillating movement, and usually appears when a person's muscles are relaxed, or at rest, hence the term "resting tremor." The affected

## 12 FREQUENTLY ASKED QUESTIONS

body part trembles when it is not performing an action. Typically, the fingers or hand will tremble when folded in the lap, or when the arm is held loosely at the side, i.e., when the limb is at rest. The tremor usually ceases when a person begins an action. Some people with PD have noticed that they can stop a hand tremor by keeping the hand in motion or in a flexed grip. The tremor of PD can be exacerbated by stress or excitement, sometimes attracting unwanted notice. The tremor often spreads to the other side of the body as the disease progresses, but usually remains most apparent on the initially affected side. Although tremor is the most noticeable outward sign of the disease, not all people with PD will develop tremor.

### **BRADYKINESIA**

Bradykinesia means "slow movement." A defining feature of Parkinson's, bradykinesia also describes a general reduction of spontaneous movement, which can give the appearance of abnormal stillness and a decrease in facial expressivity.

Bradykinesia causes difficulty with repetitive movements, such as finger tapping. Due to bradykinesia, a person with Parkinson's may have difficulty performing everyday functions, such as buttoning a shirt, cutting food or brushing his or her teeth. People who experience bradykinesia may walk with short, shuffling steps. The reduction in movement and the limited range of movement caused by bradykinesia can affect a person's speech, which may become quieter and less distinct as Parkinson's progresses.

### **RIGIDITY**

Rigidity causes stiffness and inflexibility of the limbs, neck and trunk. Muscles normally stretch when they move, and then relax when they are at rest. In Parkinson's rigidity, the muscle tone of an affected limb is always stiff and does not relax, sometimes contributing to a decreased range of motion.

People with PD most commonly experience tightness of the neck, shoulder and leg. A person with rigidity and bradykinesia tends to not swing his or her arms when walking. Rigidity can be uncomfortable or even painful.

### **POSTURAL INSTABILITY**

One of the most important signs of Parkinson's is postural instability, a tendency to be unstable when standing upright. A person with postural instability has lost some of the reflexes needed for maintaining an upright posture, and may topple backwards if jostled even slightly. Some develop a dangerous tendency to sway backwards when rising from a chair, standing or turning. This problem is called retropulsion and may result in a backwards fall.

People with balance problems may have particular difficulty when pivoting or making turns or quick movements.

Doctors test postural stability by using the "pull test." During this test, the neurologist gives a moderately forceful backwards tug on the standing individual and observes how well the person recovers. The normal response is a quick backwards step to prevent a fall; but many people with Parkinson's are unable to recover, and would tumble backwards if the neurologist were not right there to catch him or her.

### **SECONDARY MOTOR SYMPTOMS**

In addition to the cardinal signs of Parkinson's, there are many other motor symptoms associated with the disease including:

- Freezing of gait is an important sign of PD that is not explained by rigidity or bradykinesia. People who experience freezing will normally hesitate before stepping forward. They feel as if their feet are glued to the floor. Often, freezing is temporary, and a person can enter a normal stride once he or she gets past the first step. Freezing can occur in very specific situations, such as when starting to walk, when pivoting, when crossing a threshold or doorway, and when approaching a chair. For reasons unknown, freezing rarely happens on stairs. Various types of cues, such as an exaggerated first step, can help with freezing. Some individuals have severe freezing, in which they simply cannot take a step. Freezing is a potentially serious problem in Parkinson's disease, as it may increase a person's risk of falling forward.
- Micrographia is the name for a shrinkage in handwriting that progresses the more a person with Parkinson's writes. This occurs as a result of bradykinesia, which causes difficulty with repetitive actions.
- Drooling and excess saliva result from reduced swallowing movements.
- The mask-like expression found in PD, meaning a person's face may appear less expressive than usual, can occur because of decreased unconscious facial movements.
- The flexed posture of PD may result from a combination of rigidity and bradykinesia.
- Some people with Parkinson's experience movements that are too quick, not too slow. These unwanted accelerations are especially troublesome in speech and movement. People with excessively fast speech, tachyphemia, produce a rapid stammering that is hard to understand. Those who experience festination, an uncontrollable acceleration in gait, may be at increased risk for falls.

### **Do Parkinson's symptoms affect one or both sides of the body?**

By definition, Parkinson's is a progressive disease. Although some people with Parkinson's only have symptoms on one side of the body for many years, eventually the symptoms begin on the other side. Symptoms on the other side of the body often do not become as severe as symptoms on the initial side.

### **Can daily stress worsen Parkinson's symptoms?**

Stress means different things to different people and can arise from positive and negative events. Celebrations and social outings are examples of positive stressors. Injuries, conflicts, illnesses, operations, physical discomfort and sleep deprivation are examples of unwelcome stressors.

Stress does not cause PD, but stress of any kind can briefly worsen its symptoms. The increase in symptoms experienced during stressful situations is temporary and will resolve after the stress is relieved.

Paradoxically, some people may experience temporary improvements in their Parkinson's symptoms during important emotional events. Some people may surprise their family by doing especially well at a wedding or at the doctor's office when they are doing poorly at home.

### **What can a person with Parkinson's do to avoid falling?**

Falling is perhaps the most common and dangerous complication of PD as it can lead to fractures or head injuries. Contributing factors to fall risk include impaired balance, stooped posture, stiffness and slowness, gait freezing, lack of awareness of one's falling risk, fatigue and low blood pressure.

Many people with Parkinson's have a dangerous tendency to sway backward when they stand or turn, a problem called retropulsion. Others hesitate or "freeze" when taking a first step through a narrow space, when attempting to pivot or when approaching a target, such as a chair. Elevators, revolving doors, and crowded situations are especially challenging for people who experience freezing.

There are several ways to lessen the risk of falls. For example, sometimes a simple medication change can help. Others may benefit from gait training. Devices, such as canes and walkers, can be helpful for some people. Even when a cane is unnecessary for balance, it sends a signal for crowds to allow space for a person with PD. People with Parkinson's should avoid climbing or descending stairs while carrying packages in both hands. Certain treacherous



situations may require assistance: an inclined driveway, a crowded space, a broken sidewalk, obstacles on the floor or an icy pavement. For those who tend to sway backward, it is helpful to place the feet in a firm stance, and to use walls or counters for support.

**For more information:**

*Download our fact sheet "Falls Prevention" at [Parkinson.org/FactSheets](https://www.parkinson.org/FactSheets).*

*Listen to our Substantial Matters Podcast Episode #18: Stall the Fall at [Parkinson.org/Podcast](https://www.parkinson.org/Podcast).*

*View our Parkinson's Expert Briefing webinar: "Gait, Balance and Falls in Parkinson's Disease" with Terry Ellis and Becky G. Farley at [Parkinson.org/ExpertBriefings](https://www.parkinson.org/ExpertBriefings).*

*You can also request more information by calling 800-4PD-INFO.*

## What are "wearing-off spells"?

"Wearing-off" is what happens when individual doses of anti-Parkinson medications lose their long-lasting effect. In early PD, medications can work so effectively and so smoothly that many people hardly notice their symptoms. But with time, the duration of benefit following each dose begins to shorten. Several hours after a dose of medication, tremor stiffness and other PD symptoms may return.

For some, this experience is an inconvenience that can be relieved by taking an extra dose of medication. For others, wearing-off spells are unpleasant and disabling. Wearing-off spells may occur gradually and predictably, or they may happen suddenly and unexpectedly. People with Parkinson's 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 go "off," their medications have stopped providing relief, and they are stiffer and slower.

Wearing-off motor fluctuations generally develop after five years of treatment with anti-Parkinson medication. These episodes can sometimes be helped by an extra dose of a dopamine agonist or levodopa, or by shortening the time between doses. The addition of long-acting ("controlled release") levodopa (e.g., Sinemet CR or Rytary™) or a COMT inhibitor can extend the medication effect, and reduce wearing-off. Apomorphine (Apokyn®) is an injectable dopamine agonist that works within minutes, and can help with sudden wearing-off spells. In some people, these strategies may increase the likelihood of experiencing dyskinesias.

Some people with Parkinson's experience both wearing-off spells and drug-induced dyskinesias. These individuals often require a complicated medication schedule. People with these problems require close attention from a Parkinson's specialist who is knowledgeable about the many medications available to treat the disease. In addition, neurosurgical procedures for Parkinson's can be very effective at reducing wearing-off and dyskinesias.

*Learn more about Parkinson's medications on page 28.*

### **What are dyskinesias?**

Dyskinesias are involuntary twisting or writhing movements caused by dopamine medications: levodopa formulations and dopamine agonists. Dyskinesias are a complication of medical treatment for PD, and not a direct manifestation of the disease itself. These movements usually appear on the side of the body that is most affected by Parkinson's, and sometimes can involve the neck, face or trunk.

Dyskinesias generally develop after five or more years of treatment with levodopa and dopamine agonists. Long-acting Sinemet and COMT inhibitors can worsen dyskinesias. In some individuals, dyskinesias are mild and hardly noticeable. In others, they are dramatic movements that attract attention and impair coordination and gait. Dyskinesias may be more worrisome to care partners, family members and friends than they are for the person with PD (who is coping with many other issues). However, dyskinesias may cause fatigue and become painful for the individual with PD.

Dyskinesias can often be helped by medication adjustment, such as a reduction in dopamine drugs or the addition of amantadine. For the right person, deep brain stimulation may be very effective at reducing dyskinesias, and can be considered if medication adjustment is not successful. Researchers are currently looking at ways to prevent and lessen dyskinesias.

### **Do people with Parkinson's have pain?**

Painful sensations are a serious but under-recognized cause of distress for people with Parkinson's. At some point in the disease, nearly everyone experiences pain. The potential causes of physical discomfort in people with PD are numerous, and include cramping muscles, rigidity, arthritis, tendonitis, aching due to poor posture, painful contractures resulting from prolonged immobility, and painful sustained twisting or posturing, known as dystonia. Some people with Parkinson's experience uncomfortable throbbing, burning

or pulling sensations that seem to involve their inner organs, and occur when their medications wear off. Headache, a common cause of pain in the general population, is rare in Parkinson's.

In most cases, it is possible to establish the cause of pain in people with Parkinson's disease by a careful description of the complaints and a thorough neurological examination. If the pain involves a limb that assumes a twisted posture, the likely cause is dystonia. If the pain involves a rigid or immobile joint, such as the shoulder or the hip, the more likely cause is parkinsonian rigidity or arthritis.

People who suffer from pain should take note of any relationship between their discomfort and the Parkinson's medication schedule. If the pain occurs mostly when medication has worn off, it is most likely a manifestation of "off" rigidity or "off" dystonia.

For the most part, pain in PD is treatable. Depending on the cause of the pain, treatment may consist of adjustments in anti-Parkinson medication, physical therapy, anti-inflammatory agents or other types of pain medication. For severe dystonia, injections of the muscle relaxant botulinum toxin (BOTOX®, Myobloc®, Xeomin®) may be dramatically effective. For pain that occurs in the unmedicated "off" state, the best solution is to increase "on" periods through medication adjustment. All individuals who experience persistent pain should inform their neurologist.

***For more information:***

*Download our fact sheet "Pain in PD" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*View our Expert Briefing webinar: "Pain in PD" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*You can also request more information by calling 800-4PD-INFO.*

## **How can cramping in the legs and toes be relieved?**

Many people with Parkinson's experience cramps in their legs and toes. Often these symptoms occur at night and interfere with sleep. Sometimes, the cramps cause the feet and toes to assume painfully forced or twisted postures, known as dystonia. Dystonia usually occurs when medications have worn off, which typically happens in the early morning. Early morning toe dystonia can sometimes be resolved by walking. In most cases, the next dose of medication will probably relieve the symptoms. For severe symptoms, a neurologist may add an additional dose or drug (e.g., botulinum toxin) to help.

## **NON-MOTOR SYMPTOMS**

### **What are non-motor symptoms of PD?**

Most people with Parkinson's experience non-motor symptoms, those that do not involve movement, coordination, physical tasks or mobility. While a person's family and friends may not be able to see them, these "invisible" symptoms can actually be more troublesome for some people than the motor impairments of PD.

Many researchers believe that non-motor symptoms may precede motor symptoms — and a Parkinson's diagnosis — by years. The most recognizable early symptoms include loss of sense of smell, constipation, REM behavior disorder (a sleep disorder), mood disorders and neurogenic orthostatic hypotension (low blood pressure when standing up). If a person has one or more of these symptoms, it does not necessarily mean that individual will develop PD, but these markers are helping scientists to better understand the disease process.

In the following pages of this booklet, some of these important symptoms will be discussed: sleep disturbances, constipation, bladder problems, sexual problems, excessive saliva, weight loss or gain, vision and dental problems, fatigue and loss of energy. Some people may also experience depression, apathy, hallucinations, fear and anxiety. Others may have cognitive issues, such as memory difficulties, slowed thinking, confusion and in some cases, dementia. Additionally, medications can cause some side effects, such as impulsive behaviors.

### **Are sleep disturbances related to Parkinson's disease?**

People with Parkinson's often have difficulty sleeping due to nocturnal tremors, physical discomfort related to stiffness or rigidity, inability to roll over in bed, bladder problems, restlessness and painful dystonia. Many people experience vivid dreams or hallucinations and act out violent nightmares, a problem called "REM sleep disorder." Scientists believe this problem may precede a PD diagnosis by several years. Other individuals fall into a pattern of sleeping too much during the day and then having insomnia at night, causing a "sleep-wake reversal" pattern. Another pattern is the person with PD who falls asleep easily at bedtime, but then awakens in a few hours, unable to return to sleep for the duration of the night.

The importance of adequate sleep in Parkinson's cannot be overstated. People with PD with poor sleep quality or sleep deprivation find that their level of

motor function is poorer and their medications do not work as well. They may experience more mobility problems, wearing-off and dyskinesias and may experience intolerable daytime drowsiness, a concern for those who drive.

A discussion of sleep-related issues should be part of every visit to the neurologist. In all cases, it is important not to overlook medical causes of poor sleep, such as sleep apnea. Treatments for sleep disturbances typically aim to make an individual more comfortable at night.

Tips for people with insomnia include:

- Stay away from stimulants, such as caffeine, chocolate or alcohol in the evening.
- Avoid naps in the evening.
- Limit drinking fluids before bedtime to prevent frequent awakenings to urinate.

Some people are helped by an extra dose of their anti-Parkinson medications at bedtime or in the middle of the night, while others require a sleeping medication. Vivid dreams and REM sleep disorder respond to medication.

Individuals who are taking sedatives may actually find that their sleep problems worsen and so medication changes should be discussed with their doctors.

***For more information:***

*Download our fact sheet "Fatigue and Parkinson's Disease" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*View our Parkinson's Expert Briefing webinar: "Sleep and Parkinson's" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*Listen to our Substantial Matters Podcast #28: Autonomic Problems at [Parkinson.org/Podcast](http://Parkinson.org/Podcast).*

*Order our resource book *Sleep: A Mind Guide to Parkinson's Disease* at [Parkinson.org/Books](http://Parkinson.org/Books).*

*You can also request more information by calling 800-4PD-INFO.*

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

Constipation is a common problem in Parkinson's. It can be caused by slow transit time through the bowels due to muscular inertia, medication effects and diet. Lack of exercise and activity can cause or aggravate constipation. In addition, some people with Parkinson's disease experience difficulty with defecation due to rigidity and slowness of the pelvic floor muscles.

## 20 FREQUENTLY ASKED QUESTIONS

The first step to solving constipation is to increase fiber and fluid intake. For some people, this means a major dietary overhaul, which requires discipline and support. Efforts to become more active will help constipation. Stool softeners are also useful. Laxatives are available if conservative measures do not work, but it is important to use these agents correctly under the supervision of a physician.

Certain medications may be prescribed for constipation. In these cases people with PD should avoid taking metoclopramide as it can worsen PD symptoms. More aggressive measures, such as enemas, should not be used without medical supervision.

*For more information, download our fact sheet "Constipation and Other Gastrointestinal Problems in PD" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

### **Do people with Parkinson's experience bladder problems?**

Urinary urgency and frequency are common bladder problems in PD. Some describe being unable to hold their urine once they realize that they have to empty their bladder. If they also have difficulty moving quickly to a rest room, this can result in an accident. When these problems occur at night, sleep can be interrupted.

The first step in addressing bladder control issues is to speak to a neurologist. Some people will require a urological evaluation to assess the situation. In men, for example, prostate disease is a common cause of bladder malfunction that must be distinguished from Parkinson's. Treatments may include a change in the routines of fluid intake, avoidance of diuretics, bladder training, medications and sometimes, protective padding.

For nighttime frequency, it is wise to omit fluid in the evening and to avoid caffeine in any form. It is important to note that many of the medications for incontinence may cause memory difficulties, a factor that needs to be considered in people with Parkinson's with cognitive problems.

*For more information download our fact sheet "Urinary Problems in Parkinson's Disease" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

## Are sexual problems common in people with Parkinson's?

The evidence from research studies demonstrates that people with Parkinson's can enjoy and experience a fulfilling sexual relationship just as well as healthy individuals. However, people with PD are prone to different types of sexual problems. Men may experience difficulty achieving erections. Women complain of vaginal dryness and inability to experience orgasm. Both men and women may suffer from a loss of libido due to PD. Impaired bladder control due to Parkinson's can have an impact on sexual performance. In addition, depression, common for people with PD, can increase sexual difficulties.

Many of these problems can be helped, so it is important to discuss these issues with a neurologist. For example, there are now medications that can improve erectile dysfunction. Testosterone treatments may improve libido in women and men.

Parkinson's is sometimes associated with hyperactive behaviors. In a minority of individuals with Parkinson's, medications such as dopamine agonists and levodopa have caused inappropriate hypersexuality. This problem has a potentially serious impact on the person with Parkinson's and his or her life partner, and must be brought to the attention of the neurologist.

*Learn more about these side effects and medications on pages 30 and 31.*

## Why do people with PD have excessive saliva?

### What can be done to address this problem?

Excessive saliva in people with Parkinson's disease does not result from increased saliva production. In fact, saliva production is decreased in PD. Excessive salivation and drooling are caused by a lack of spontaneous swallowing, which allows saliva to overflow, and by slowness of the tongue, mouth and throat muscles. In addition, a flexed neck posture will cause saliva to accumulate at the front of the mouth, which leads to drooling.

Medications for PD can reduce drooling by increasing the mobility of swallowing muscles. Improved neck posture will help. Some people suck on sour candies to trigger the swallowing reflex. If drooling persists, medications can be prescribed to restrict saliva production and cause dry mouth, but these may have side effects, such as memory impairment or constipation. Severe drooling can be treated using salivary gland injections with botulinum toxin. Surgery has been used for drooling in other conditions, but these measures are rarely necessary.

### **Is it true that Parkinson's disease can cause dental problems?**

Certain symptoms of Parkinson's can complicate dental health for people living with Parkinson's. Motor symptoms such as tremor may make tooth brushing and flossing more difficult. Since saliva production is actually reduced in PD, this can lead to tooth decay or cavities. Dyskinesias, poor mobility, tremor and swallowing difficulties may make visits to the dentist more challenging. Helpful strategies include taking levodopa before dental appointments and scheduling visits early in the morning to avoid long waiting times.

*For more information, download our fact sheet "Dental Health and Parkinson's Disease" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

### **What vision changes do people with Parkinson's sometimes experience?**

Some people with Parkinson's notice that as the disease progresses, their vision loses sharpness or becomes blurred, and they have trouble with dry eyes. Some vision difficulties are related to changes in the movement of the eyeball. These are motor symptoms, similar to other motor symptoms caused by loss of dopamine neurons. Difficulties related to the eyes and vision often progress alongside other PD symptoms. It may be helpful to see a neuro-ophthalmologist, a specialist either in ophthalmology or neurology, who has additional training in diagnosing and treating problems with the eyes and with vision that are associated with PD and other neurological diseases.

### **Is low blood pressure and lightheadedness a problem in Parkinson's disease?**

Neurogenic orthostatic hypotension (nOH), or low blood pressure, is a sharp drop in blood pressure that happens when a person gets up from bed or from a chair, causing dizziness or even loss of consciousness. Doctors define it as a blood pressure drop of 20 millimeters of mercury (20 mm Hg) in systolic blood pressure (the top number in a blood pressure reading), or a drop of 10 millimeters in diastolic blood pressure (the bottom number), within three minutes after standing up. Both Parkinson's itself, and the medications that are used to treat it, can contribute to nOH. In addition, people with Parkinson's may be on other medications that affect blood pressure.

This condition can put people with Parkinson's at risk of fainting, losing balance, falling, and being injured. To reduce the risk of nOH, it is important to avoid dehydration. People with PD should ask their doctor to identify



medications that may lower blood pressure, and see if a change in dose is indicated. Also, avoid abrupt changes in position. Medicinal approaches may include midodrine (ProAmatine®), fludrocortisone (Florinef®), pyridostigmine (Mestinon®) or droxidopa (Nothera®).

*For more information, download our fact sheet "Neurogenic Orthostatic Hypotension" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

### **Is depression a common problem in Parkinson's disease?**

At least 60 percent of people with Parkinson's may experience mild or moderate depressive symptoms at some point during the disease.

Mild depression causes feelings of sorrow, discouragement and passivity, which may be temporary and normal reactions to the disappointments in everyday life. At the other end of the spectrum, depression can cause an extreme state of hopelessness, low self-esteem or the desire to harm oneself, coupled with severe changes in behavior including insomnia, increase in or loss of appetite, loss of interest in daily activities and social isolation. Some people with depression may also experience feelings of anxiety or panic. In its most severe form, depression can cause a wish to die, which, if untreated, may lead to suicide attempts.

When a person with PD experiences symptoms of depression, it is important to bring these symptoms to the attention of a medical professional. Often, depression can be lifted by an adjustment in medication. Diet, exercise, improved sleep quality and re-engagement in daily routines can also help depression. Many people can benefit from both therapy and antidepressants. There are effective treatments that will not interact negatively with anti-Parkinson medications. However, drugs used to treat depression in PD may differ from those used in people without Parkinson's. For pronounced or sustained symptoms, a physician may recommend a consultation with a psychiatrist.

#### **For more information:**

*Download our fact sheet "Combatting Depression" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*View our Parkinson's Expert Briefing webinar "Depression and PD: Treatment Options" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*Request a copy of our resource book *Mood: A Mind Guide to Parkinson's Disease*, at [Parkinson.org/Books](http://Parkinson.org/Books).*

*You can also request more information by calling 800-4PD-INFO.*

## **What is the relationship between apathy and Parkinson's?**

Apathy is increasingly recognized as a common symptom of Parkinson's disease — affecting about 40 percent of people with Parkinson's without cognitive impairment and 60 percent of people with PD with cognitive impairment. Older men with more severe PD symptoms are particularly likely to experience apathy.

Apathy, similar to PD movement symptoms, is thought to result from a loss of dopamine in the brain. It can develop before a PD diagnosis, or at any stage of disease progression.

Overcoming apathy starts with self-awareness, being in the best possible health, and ruling out other causes for feeling sluggish. There are no approved medications to treat apathy, but some people with PD may benefit from cholinesterase inhibitors (rivastigmine, etc.), stimulants, or certain types of antidepressants.

## **Is dementia part of Parkinson's?**

Nearly all people with Parkinson's will experience some degree of cognitive change. Unfortunately, many people will eventually develop a mild form of dementia that may impact their ability to function independently.

Those who develop dementia may experience slowed thought processes, memory problems, difficulty concentrating, apathy and poor motivation, word-finding difficulty or poor judgment. Some people have particular difficulty with complicated tasks or tasks involving visual space, a potential issue in driving. Studies suggest that dementia is more common in people who develop Parkinson's after age 60, or in people whose PD is characterized primarily by slowness or bradykinesia. People with PD and dementia seem to obtain less benefit from their anti-Parkinson medications, and are more likely to experience sedation and hallucinations.

Cognitive problems can have a major impact on quality of life, and should be discussed with a neurologist. For some people, reducing the dose of Parkinson's medications can help to improve mental clarity. Engaging in mental games and problem-solving can help to exercise the mind. There are several medications available to treat dementia, mainly borrowed from the Alzheimer's treatment trials. For example, rivastigmine tartrate (Exelon®) is approved for treatment

of mild to moderate Parkinson's dementia. Because depression can sometimes masquerade as dementia symptoms, it is important that people with Parkinson's with cognitive problems be carefully screened for depression, and treated if necessary.

**For more information:**

Download "Cognition in Parkinson's " at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).

Request a copy of our resource book *Cognition: A Mind Guide to Parkinson's Disease*, at [Parkinson.org/Books](http://Parkinson.org/Books).

View our Parkinson's Expert Briefing webinar: "Cognition and PD: What You've Always Wanted to Know But Were Too Afraid to Ask" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).

Listen to our Substantial Matters Podcast #27: *More Than Movement: Addressing Cognitive and Behavioral Challenges in Caring for PD* at [Parkinson.org/Podcast](http://Parkinson.org/Podcast).

You can also request more information by calling 800-4PD-INFO.

## Do people with PD experience hallucinations?

Hallucinations are common in Parkinson's and are usually considered a side effect of dopamine medication. People with PD generally experience visual hallucinations in the evening or at night, when visibility is reduced. Sometimes a person with Parkinson's will imagine small animals or children, perceive faces, or have the impression of figures standing in his or her presence. In some cases, the hallucinations are threatening or are part of a paranoid delusion. Most people are aware that their hallucinations are a trick of the mind, but others find them convincingly real.

People who experience hallucinations, vivid dreams or unusual ideas, should inform their neurologist. These phenomena are likely to be induced by medication, particularly by dopamine agonists, and can often be eliminated by adjusting the dose. Reducing dopamine medication in the evening may eliminate nighttime visions. Sometimes, hallucinations are persistent and require treatment using an antipsychotic agent, such as pimavanserin (Nuplazid®), quetiapine (Seroquel®), clozapine (Clozaril®) or medications called acetylcholinesterase inhibitors.

***For more information:***

*View our video "Hallucination in Parkinson's Disease" on the Parkinson's Foundation YouTube Channel.*

*Request a copy of our book *Psychosis: A Mind Guide to Parkinson's* at [Parkinson.org/Books](http://Parkinson.org/Books).*

*View our Parkinson's Expert Briefing webinar: "Parkinson's Disease Psychosis: Hallucinations, Delusions and Paranoia" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*Listen to our Substantial Matters Podcast #23: Hallucinations and Delusions in Parkinson's at [Parkinson.org/Podcast](http://Parkinson.org/Podcast).*

*You can also request more information by calling 800-4PD-INFO.*

## **Can Parkinson's or its medications cause compulsive behaviors such as gambling and shopping?**

The reward system of the human brain is governed by dopamine, the same chemical that is deficient in Parkinson's. Because the medications for PD stimulate the brain's dopamine systems, some individuals develop addictive and compulsive behaviors called impulse control disorders (ICDs).

The most common addictive behaviors triggered by excessive dopamine include compulsive shopping, compulsive gambling, compulsive sexual urges and binge eating. If unchecked, these behaviors can be costly.

These compulsive behaviors usually result from medication. Dopamine agonists, such as pramipexole (Mirapex®), ropinirole (Requip®) or rotigotine transdermal system (Neupro®), are most likely to cause compulsive behaviors, but any compound that stimulates the dopamine system can provoke them. If a person with PD develops an uncharacteristic change in behavior of this type, it is important to immediately alert the neurologist, who can often resolve the problem by reducing or changing a medication.

*For more information, download our fact sheet "Impulse Control and PD" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

## CHAPTER TWO

# Treating Parkinson's

## FINDING A DOCTOR

### How can a person find a doctor who is knowledgeable about Parkinson's?

Finding the right physician is important. Treating Parkinson's requires a team approach involving not only the person living with Parkinson's, but also family members, the physician and other healthcare professionals. Every person has different Parkinson's issues, vulnerabilities and needs.

The Parkinson's Foundation maintains that people with Parkinson's are best served by a movement disorder specialist who is an expert in all aspects of the disease, knowledgeable regarding the full range of treatment options, and familiar with the cutting edge of clinical and scientific research. The ideal Parkinson's physician is available to provide advice and care, and is responsive during times of need.

Some people with Parkinson's may not have a specialist in their immediate geographic area. When a person cannot find a local expert, it may be worthwhile to travel once or twice a year to see a specialist who can work together with the local general neurologist to provide the best care possible. To find a Parkinson's specialist, a person can solicit recommendations from other people living with PD, such as members of a local support group, or

can call his or her health care provider and ask for a list of specialists in the covered network. The foundation also maintains a list of Parkinson's specialists around the US. Please call our Helpline at 800-4PD-INFO or email [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org) for assistance.

### **For more information:**

*Download our fact sheet "Seeking Out a Specialist" at [Parkinson.org/FactSheets](https://www.parkinson.org/FactSheets).*

*Listen to our Substantial Matters Podcast #30: Team Care for PD:*

*Why It's Important at [Parkinson.org/Podcast](https://www.parkinson.org/Podcast).*

*You can also request more information by calling 800-4PD-INFO.*

### **How often should people with Parkinson's see a doctor?**

Most people with PD are advised to see their doctor every three to six months, especially if they are taking anti-Parkinson medications. If a person is experiencing problems with his or her condition or treatment, more frequent visits may be warranted. Some people remain in regular contact with their doctors by telephone, email or online patient portal. For people who urgently need to speak with their physician or schedule a visit, the most direct method of contact is the telephone.

## **MEDICATIONS & SURGICAL TREATMENTS**

### **What are the treatment options for PD?**

Parkinson's is a very individualized disease and each person who lives with it requires a unique treatment plan. Although researchers are attempting to develop treatments that will slow down or reverse the disease, no such therapy is currently proven to be clinically effective. The goal of treatment is to reduce symptoms and to allow a person to function as normally, and with as few side effects, as possible. Current treatment options include medications and surgery. It is common for people to take a variety of medications — all at different doses and times of the day — in order to manage the symptoms of the disease.

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

There are many effective medications for Parkinson's symptoms. The six major categories, or classes, include: (i) levodopa, (ii) dopamine agonists, (iii) COMT (catechol-O-methyl transferase) inhibitors, (iv) MAO (monoamine oxidase) B inhibitors, (v) anticholinergics and (vi) other medications including amantadine (Symmetrel®). Within each class of drug, there are many options. These are listed on the following pages.

Most Parkinson's medications work by influencing dopamine, the brain chemical that plays an important role in behavior, coordination and mobility. Dopamine drugs are associated with potential side effects, including nausea, drowsiness, low blood pressure, hallucinations, writhing movements (dyskinesias) and compulsive behaviors.

For many people, the choice of medication is dictated by side effects and tolerability. While the ideal medication program is simple, for some individuals, the medication schedule can become quite complicated, with multiple agents taken around the clock. The goal of treatment — to keep a person functioning and enjoying life at the highest level — is the same at every stage of the disease. It is important to note that medications work best when they are taken on a regular schedule, and when combined with exercise, good nutrition and adequate sleep.

#### **LEVODOPA**

The most potent medication for Parkinson's is levodopa. Its development in the late 1960s represents one of the most important breakthroughs in the history of medicine. Plain levodopa produces nausea and vomiting. It is now combined with carbidopa to prevent this side effect. The well-known combined carbidopa/levodopa formulation is called Sinemet®.

There are many different preparations and strengths of carbidopa/levodopa, including controlled release (Sinemet CR®), extended release (Rytary™), a formulation that dissolves in the mouth without water, called Parcopa®, and a gel formulation of the drug called Duopa™ that requires a surgically-placed tube. There is a combined formulation that includes the COMT inhibitor entacapone, called Stalevo®.

It is important that people with PD are aware which levodopa preparation they are taking because there are so many different pill sizes, strengths and manufacturers. Be careful when renewing prescriptions at the pharmacy because the accidental substitute of a different formulation may lead to an overdose or underdose.

Carbidopa/levodopa remains the most effective drug for treating Parkinson's. Some people with PD have been reluctant to take it, believing it to be a last resort. But most neurologists agree that delaying treatment too long is unwise, and may put a person with PD at risk for falling. The decision about when to start carbidopa/levodopa is different for every person with Parkinson's, and requires consideration of potential benefits, risks and the availability of alternatives.

### **DOPAMINE AGONISTS**

Dopamine agonists are drugs that stimulate the parts of the human brain influenced by dopamine. In effect, the brain is tricked into thinking it is receiving the dopamine it needs. In general, dopamine agonists are not as potent as carbidopa/levodopa, and therefore are less likely to cause dyskinesias. Dopamine agonists can be taken alone or in combination with medications containing levodopa. The two most commonly prescribed oral pill agonists in the US are pramipexole (Mirapex) and ropinirole (Requip). A third, rotigotine transdermal system (Neupro®), is available in a patch form. Bromocriptine (Parlodel®) is available, but is less commonly used.

As a class, dopamine agonists may cause nausea, hallucinations, sedation (including sudden sleepiness, called sleep attacks) and lightheadedness due to low blood pressure, so it is important to start at a low dose, increase gradually and be alert for side effects. In some people (in a recent study up to 14 percent), these medications have also been linked with compulsive behaviors, such as gambling and shopping.

*Learn more about these side effects on pages 25 and 26.*

One dopamine agonist, apomorphine (Apokyn), is a powerful and fast-acting injectable medication that promptly relieves symptoms of PD within minutes, but only provides 30 to 60 minutes of benefit. With training provided by the Parkinson's specialist, people with PD, spouses and family members can be taught to administer the agent, using a pre-filled syringe system. Its main advantage is its rapid effect. It is used for people who experience sudden wearing-off spells when their Parkinson's medication abruptly stops working, leaving them unexpectedly immobile. Apomorphine may cause severe nausea, and so people using this agent must take an antiemetic agent. In addition, apomorphine can provoke dyskinesias and other side effects associated with dopamine drugs.

### **COMT INHIBITORS**

COMT inhibitors such as entacapone (Comtan®) and tolcapone (Tasmar®) represent the newest class of Parkinson's medications. These agents have no direct effect on PD symptoms, but are used to prolong the effect of levodopa by blocking its metabolism. COMT inhibitors are used primarily to help with the problem of wearing-off, in which the effect of levodopa becomes short-lived. People who take Tasmar must have regular liver function blood tests. Entacapone is not only a COMT inhibitor, but is also one of the main ingredients in Stalevo.



**MAO-B INHIBITORS**

The two MAO-B inhibitors — selegiline (also called deprenyl, with trade names Eldepryl® and Zelapar®) and rasagiline (Azilect®) — block an enzyme in the brain that breaks down levodopa. These drugs have a modest effect in suppressing the symptoms of PD. They have been shown to delay the need for Sinemet when prescribed in the earliest stage of Parkinson's, and have been approved for use in later stages of PD to boost the effects of Sinemet.

**AMANTADINE**

Generic amantadine medication is used for off-label treatment of Parkinson's dyskinesia. The only FDA approved extended-release amantadine treatment, Gocovri™, was approved for treating Parkinson's dyskinesia that occurs with dopamine medication. Generic amantadine is a well tolerated drug, but its potential side effect include dry mouth, constipation, bladder problem, ankle swelling and skin rash.

**ANTICHOLINERGICS**

Anticholinergics can be helpful for tremor and may ease dystonia associated with wearing-off or peak-dose effect. They have little effect on other symptoms of Parkinson's. The drugs in this class include trihexyphenidyl (Artane®) and bztropine mesylate (Cogentin®) among others. They do not act directly on the dopaminergic system. Instead, they decrease the activity of acetylcholine, a neurotransmitter that regulates movement. Potential adverse effects include blurred vision, dry mouth, constipation and urinary retention. Older individuals are susceptible to confusion and hallucinations on anticholinergics, so these agents should be avoided in individuals over the age of 70.

***For more information:***

*Request a copy of our resource book: Medications at [Parkinson.org/Books](http://Parkinson.org/Books).*

*Download our fact sheets "Medications On Time, Every Time," "Maximizing PD Medications" and "Medications and Schedule" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*View our Parkinson's Expert Briefing webinars: "Medication Side Effects," and "Maximizing PD Medications: Get the Most Out of Your Treatment Plan" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*Listen to Substantial Matters Podcast #6: New Levodopa Delivery Methods for Parkinson's at [Parkinson.org/Podcast](http://Parkinson.org/Podcast).*

*You can also request more information by calling 800-4PD-INFO.*

## Medications Currently Approved for Treatment of Parkinson's Disease

### CLASS/TYPE    MEDICATION

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**L-DOPA**            Carbidopa/Levodopa (Sinemet®)  
 Carbidopa/Levodopa orally disintegrating tablet (Parcopa®)  
 Carbidopa/Levodopa controlled release (Sinemet CR®)  
 Carbidopa/Levodopa/Entacapone (Stalevo®)  
 Carbidopa/Levodopa Extended Release Capsules (Rytary™)  
 Carbidopa/Levodopa Enteral Suspension (Duopa™)  
*This is a gel formulation of the drug that requires a surgically-placed tube.*

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**Dopamine Agonists**            Apomorphine (Apokyn®)  
 Bromocriptine (Parlodel®)  
 Pramipexole (Mirapex®)  
 Pramipexole dihydrochloride extended-release (Mirapex ER®)  
 Ropinirole (Requip®)  
 Ropinirole extended-release tablets (Requip® XLTM)  
 Rotigotine transdermal system (Neupro®)

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**COMT Inhibitors**            Entacapone (Comtan®)  
 Tolcapone (Tasmar®)

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**MAO-B Inhibitors**            Rasagiline (Azilect®)  
 Selegiline or deprenyl (Eldepryl®)  
 Selegiline HCl orally disintegrating tablet (Zelapar®)  
 Safinamide (Xadago®)

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**Anticholinergics**            Benztropine mesylate (Cogentin®)  
 Procyclidine *Not currently available in the US.*  
 Trihexyphenidyl (Artane®)

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**Other**                            Amantadine Extended Release (Gocovri®)  
 Droxidopa (Northera™)  
 Pimavanserin (Nuplazid™)  
 Rivastigmine tartrate (Exelon®)

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More details on all of these medications can be found at [Parkinson.org](http://Parkinson.org).

## What drug should be used first?

Fifty years after its discovery, levodopa remains the most effective medication for Parkinson's disease, and the "gold standard" by which all treatments for Parkinson's are measured. It still remains uncertain whether levodopa has a long-term effect on the biology of Parkinson's, but there is no question that it has increased the lifespan of and dramatically improved the quality of life for millions of people worldwide.

Some experts advocate early treatment with levodopa because the drug is the most effective at suppressing the symptoms of Parkinson's. Others contend that dopamine agonists are nearly as effective as levodopa in improving quality of life, especially in the early stages of PD. Dopamine agonists appear less likely to provoke fluctuations and dyskinesias, two long-term complications of treating PD. Still others argue that the wearing-off spells and fluctuations would occur anyway because they reflect the progression of disease.

Despite lively debates in medical literature, no viewpoint has been proven. The argument that levodopa should be postponed as long as possible because it only works for a limited period of time, is not valid.

A reasonable compromise adopted by many experts is to treat early-stage Parkinson's using milder medications, such as amantadine, dopamine agonists, or MAO-B inhibitors, and to add levodopa later, if required for symptom control. In people with PD older than 70 years, dopamine agonists can be associated with hallucinations and sedation, so using levodopa as a first-line drug is preferable in this group.

## What is deep brain stimulation?

Deep brain stimulation (DBS), was developed in the 1990s and first approved by the US Food and Drug Administration in 1997. DBS is now a standard treatment that has been used successfully in tens of thousands of people. Although it is certainly the most important therapeutic advance since the development of levodopa, DBS is not for every person with Parkinson's. It is most effective — sometimes dramatically so — for individuals who experience disabling tremors, wearing-off spells, slowness of movement and medication-induced dyskinesias.

During DBS, electrodes are inserted into a deep brain region, using MRI and neurophysiological mapping to ensure accurate placement. DBS can be directed to different parts of the brain, including the subthalamic nucleus, globus pallidus and thalamus, all crucial regions for mobility and tremor control. The choice of target depends upon a person's symptoms.

### **DBS TARGETS**

In recent years, the subthalamic nucleus has become the preferred target in the majority of people with Parkinson's. For those who have symptoms on both sides of the body, the surgery must be performed on both sides of the brain. A device called an implantable pulse generator or IPG (similar to a pacemaker) is inserted under the collarbone to provide a continuous electrical current to a part of the brain involved in motor function. After the surgery is performed, the person must return to the medical center at regular intervals for programming of the implanted device. Individuals are given a hand-held device, similar to a television remote control, which allows them to check the battery and to turn their device on or off. An IPG battery lasts for about three to five years and is relatively easy to replace under local anesthesia.

### **EFFECTS OF DBS**

As with medications, surgery for Parkinson's is not a cure. But, when used on eligible individuals, it is very effective in suppressing some symptoms, including tremor, bradykinesia and rigidity. Wearing-off spells and dyskinesias can also be significantly reduced. Some people with PD can decrease medication intake by 50 percent or more. Unfortunately, surgery does not help balance or gait freezing and has limited effects on speech or posture — all symptoms that may worsen as the disease progresses.

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

Not every person with Parkinson's is a good candidate for surgery. The ideal candidate is responsive to individual doses of levodopa but has reached a stage associated with wearing-off spells or dyskinesias. The individual should have no cognitive or emotional impairment and must be in good general health. People with forms of parkinsonism that respond poorly to levodopa or who experience cognitive or emotional difficulties, such as dementia, depression, apathy or anxiety, will not benefit from surgery.

Surgery for PD is best performed at a center with established expertise in these advanced techniques. The ideal center is one that has neurosurgeons who are trained in DBS surgery and a dedicated team of personnel available for screening, post-operative care and programming of the deep brain stimulator. It is important that a person with PD who is considering surgery be well-informed about the procedures and realistic in his or her expectations. An effective support system of family or friends is essential to help the person cope with the emotional demands of the surgery.

*For more information, request your copy of our resource book:  
Guide to Deep Brain Stimulation at [Parkinson.org/Books](http://Parkinson.org/Books).*

*You can also request more information by calling 800-4PD-INFO.*

## COMPLEMENTARY & ALTERNATIVE THERAPIES

### What other therapies are available to a person with Parkinson's?

A comprehensive and multi-disciplinary approach to health care can be very beneficial at any stage of Parkinson's.

Building a "healthcare team" involves taking advantage of not only the expertise of a PD specialist, but also the help of a physical therapist, occupational therapist, speech therapist, nutritionist, social worker and others. Some people with PD may be able to find all of these professionals in one practice or center, but many will have to explore their community's resources.

**PHYSICAL THERAPISTS** can help a person to improve mobility, flexibility, muscle strength, exercise tolerance and balance. For individuals who experience difficulties turning in bed, arising from a chair, or exiting a car, physical therapy can provide solutions. Physical therapists that are knowledgeable about PD can teach techniques for coping with freezing and avoiding falls. In addition, physical therapists can provide advice about assistive devices, such as canes or walkers, if needed.

**For more information:**

Download our fact sheet "Physical Therapy in PD" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).

View Parkinson's Expert Briefing webinar: "Physical Therapy & PD: What You Need to Know" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).

You can also request more information by calling 800-4PD-INFO.

**OCCUPATIONAL THERAPISTS** teach people alternative methods of performing daily tasks that may pose a challenge, such as eating and dressing. Occupational therapists can also evaluate a home and give suggestions to make the home safer and easier to navigate. These tips may allow a person with Parkinson's to maintain a greater level of independence.

**For more information:**

Download our fact sheet "Occupational Therapy" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).

View our Parkinson's Expert Briefing webinar: "Occupational Therapy and Parkinson's: Tips for Healthy Living" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).

You can also request more information by calling 800-4PD-INFO.

**SPEECH THERAPISTS** can help with vocal training programs including certain programs that are tailored to the needs of people with Parkinson's. For example, the Lee Silverman Voice Treatment® (LSVT®) technique is aimed

specifically at people with Parkinson's to improve vocal loudness and articulation. Speech therapists are also skilled in the evaluation and treatment of swallowing difficulties in PD.

**For more information:**

*Request a copy of our resource book: [Speech and Swallowing at Parkinson.org/Books](http://Parkinson.org/Books).*

*View our Parkinson's Expert Briefing webinar: "Improving Communication in Parkinson's Disease: One Voice, Many Listeners" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*You can also request more information by calling 800-4PD-INFO.*

Other people may benefit from consultation with nutritionists, social workers, psychologists or psychiatrists. A neurologist may be able to provide recommendations and referrals for therapy. Insurance may not cover all forms of therapy; sometimes supporting letters of necessity from the treating physicians are needed. It is important that all professionals collaborating in the care of a person with Parkinson's be aware of each other and communicate regularly, especially with regard to the treatments that each is prescribing.

## **Do acupuncture, hypnosis or massage therapies have a role in treating PD?**

Acupuncture involves the insertion of very fine needles into the skin at particular points on the body. Hypnosis is aimed at inducing a psychological state of relaxation and responsiveness that can be directed towards controlling muscles. Massage therapy is used for muscle relaxation.

None of these techniques have been rigorously tested in treating PD. There is no scientific evidence that acupuncture, hypnosis or massage therapies have any effect on the disease itself, although people with PD report they can temporarily provide relief from aching muscles and certain PD symptoms.

Alternative physical activities, such as yoga and Tai Chi, encourage disciplined movements and rigorous posture, and like conventional forms of exercise, appear to be of benefit to individuals who can practice them.

## **Is there a role for vitamins or natural supplements in treating Parkinson's?**

Many people add vitamins and other compounds to their treatment regimen. They may use antioxidants such as vitamin B6, vitamin E, vitamin C, Coenzyme Q10, glutathione and others, in the hope of slowing the disease. Others take

vitamin D, which is essential for bone health. Some research has indicated that vitamin D levels are low in people with PD.

There is no research yet to demonstrate that these substances stop or slow the progression of PD. Recent well-designed clinical trials have concluded that vitamin E, coenzyme Q10 and creatine do not slow the progression of disability in PD. While most of these substances are not harmful and will not interfere with the absorption of the various anti-Parkinson medications, the treating doctor should be kept informed of all of the supplements a person is taking.

## EXERCISE & NUTRITION

### How is exercise beneficial for people with Parkinson's disease?

Parkinson's is a disease of stiffness, slowness, fatigue and weakness. Because of this, many people find exercise challenging and may not want to exercise for fear of becoming exhausted. But research shows that certain types of physical activity can ease symptoms. For example, exercise or physical therapy can help to maintain and improve mobility, strength, flexibility and balance. Other studies have shown that exercise provides benefits that complement the effects of medications. Exercise may also help to ease many of the disease's secondary symptoms, such as depression and constipation.

People who stretch, bend and move about during the day achieve consistent results. New research suggests that intense, complex exercise (walking on a treadmill or running) also has benefits for PD symptoms.

Popular options for exercise include dancing, Tai Chi, walking, boxing and swimming. Individuals with gait difficulties or balance impairment can be helped by performing specific exercises. A physical therapist can help design an appropriate program. Strategies to break out of freezing episodes and to prevent backwards falling can be developed. There are also many classes, books and videos on exercises for PD. In order to have physical therapy covered under Medicare or insurance, a doctor must "prescribe" it. It is essential to practice physical activities after a course of therapy is finished.

#### **For more information:**

*Download our fact sheet "Exercise and Parkinson's" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*Request your copy of our resource book *Fitness Counts* at [Parkinson.org/Books](http://Parkinson.org/Books).*

*You can also request more information by calling 800-4PD-INFO.*

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

A balanced, nutritious diet is important in Parkinson's. Unfortunately, many people with Parkinson's have a poor appetite and inadequate food intake. Medications sometimes cause nausea or reduce the wish to eat. Poor appetite can lead to undesirable weight loss. In addition, problems with swallowing can cause a person to have difficulty eating nutritious foods, such as vegetables, which can impact nutritional intake.

The best plan is to maintain a full diet with all of the daily nutritional requirements. Certain habits may help with this goal. Some people who take levodopa, for example, may find that a protein meal will inactivate a dose of medication. Limiting protein intake or staggering the medication dosing to avoid conflicts with meals can help solve this problem.

Other tips:

- To be most effective, levodopa preparations should be taken up to an hour before meal- times on an empty stomach or with a dry cracker or toast.
- To prevent constipation, it's important to eat fresh fruits and vegetables, which provide fiber, drink plenty of fluids and get regular exercise.
- For people who experience difficulty swallowing, a diet of soft foods that supplements nutrients may be recommended. Adding thickening agents to thin liquids may also be recommended.
- People with Parkinson's who progressively lose weight for no clear reason should bring this symptom to the attention of their physician, and undergo a thorough medical evaluation.

### **For more information:**

*Download our fact sheet "Nutrition and Parkinson's" at [Parkinson.org/FactSheets](https://www.parkinson.org/FactSheets).  
View our Parkinson's Expert Briefing webinar: "Nutrition and Parkinson's Disease" at [Parkinson.org/ExpertBriefings](https://www.parkinson.org/ExpertBriefings).*

*Listed to our Substantial Matters podcast #4: The Importance of Good Nutrition for People with Parkinson's at [Parkinson.org/Podcast](https://www.parkinson.org/Podcast).*

*You can also request more information by calling 800-4PD-INFO.*



A grayscale photograph of a person standing in a field, looking down at a dog. The dog is sitting and looking up at the person. The background shows a hilly landscape with trees and a clear sky.

## CHAPTER THREE

# Living with Parkinson's

### FINDING SUPPORT

#### How can people with Parkinson's 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 living with young onset PD or care partners. Support groups may provide educational programs and organize members to raise awareness on a local level.

The Parkinson's Foundation keeps an unpublished listing of Parkinson's support groups to share with callers to its Helpline. Individuals looking for a referral to a nearby group can call us at 800-4PD-INFO or email us at [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org). Individuals looking to add their group to this list are also invited to contact the Helpline with group information. If a group is not available in your community, there are several Internet-based groups that may be helpful.

*For more information on support groups, download our Support Group Guide at [Parkinson.org/Library](https://www.parkinson.org/Library).*

*You can also request more information by calling 800-4PD-INFO.*

## STAYING INDEPENDENT

### **Is special equipment recommended to help people with Parkinson's?**

For those who have problems with mobility and balance, a walking device, such as a cane or walker, can help to avoid a fall. These devices provide support and serve as a reminder to step deliberately. There are many models of walkers available, differing in the number and size of wheels, the type of brakes, the amount of support, seats and baskets. Some walkers have a laser beam display to "cue" stepping for people who experience freezing.

For people who develop severe balance impairment, sometimes either a wheelchair or motorized scooter is best. Physical and occupational therapists can provide training on how to use such equipment properly.

If hand coordination becomes difficult, special utensils that facilitate eating and other daily activities can be of assistance. There are furnishings and devices, such as shower chairs, that are helpful in the bathroom. Some people who have difficulty climbing stairs find electric stair climbers to be beneficial. Voice amplifiers can help the problem of inaudible speech. Adaptive devices to enable people with PD to use computer equipment are also available.

Before buying an expensive piece of equipment, a person should talk with his or her neurologist for recommendations and obtain a referral to the appropriate therapist, who can help determine the best choice of device and give instruction on using it properly. For expensive items, a prescription from the neurologist stating that it is required may help to have the costs covered by Medicare or private insurance.

*For information on the role that service dogs can play in making life easier for people with PD, download our fact sheet "Service Dogs for PD" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

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

There are programs that will help to offset the financial difficulties presented by Parkinson's — such as the costs of home adjustments, medical equipment and medications.

The Melvin Weinstein Parkinson's Foundation (MWPF), is available for individuals who meet certain eligibility requirements. For these individuals, the fund offers one time assistance for such costs as home health care and the purchase of medical equipment, such as wheelchairs, walkers and canes. For more information, visit [www.mwpcf.org](http://www.mwpcf.org) or call 757-313-9729.

Another suggestion is to find the closest Area Agency on Aging office through the Eldercare Locator Service at [www.eldercare.gov](http://www.eldercare.gov) or 800- 677-1116. This resource links seniors to financial aid and related programs. Such programs include assisting individuals with referrals and/or applications for food stamps, Meals-on-Wheels, Medicaid/Medicare, Low Income Energy Assistance programs, low cost senior housing options and more.

Lastly, several pharmaceutical companies offer programs to help eligible applicants reduce medication costs. Visit [Parkinson.org](http://Parkinson.org) to see a list of current programs.

### **Should a person with PD drive?**

Driving poses a difficult issue for people with PD and their families. Most states do not have guidelines regarding Parkinson's and driving. However, people with PD must take extra caution as they may have slowed reaction times, impaired ability to process visual and spatial information, or problems with judgment. A fender bender, or a tendency to veer across lanes or around corners, calls into question a person's ability to judge distances accurately. People with unpredictable wearing-off spells may find themselves suddenly unable to move behind the wheel. Others may become sleepy while driving due to medication effects or to sleep deprivation from insomnia. Rarely, people with PD who experience daytime sleepiness can have "sleep attacks," without warning.

The general rule is that when family members feel concerned about their loved one's driving, it is time to evaluate the situation. Doctors are not required to report the Parkinson's diagnosis to motor vehicle bureaus, but they can insist on a driving test. If everyone agrees that an individual with Parkinson's is a potential driving risk, it is time to turn over the keys to a spouse, family member or friend.

*For more information, download our fact sheet "Driving and Parkinson's" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

### **Is it okay to drink alcohol?**

Moderate consumption of alcohol (an occasional cocktail or a glass of beer or wine) should be acceptable for people with Parkinson's, as long as they do not have other medical conditions or take medications that prohibit alcohol use.

## 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 advice; take on new household tasks such as paying bills and attending doctor appointments; and may help with personal care tasks, such as helping a loved one to dress and 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 protecting the person with PD and encouraging independence.

Some people may no longer wish to perform tasks of daily living and may actually be suffering from depression and apathy. It is important that this be recognized as separate from the physical challenges of Parkinson's and discussed with the neurologist, since medication or therapy may be necessary.

*For more information, download fact sheets "Adding Family, Friends & Volunteers to Your Caregiving" and "How to Talk With Your Family About Parkinson's" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

## Are there resources to assist family members of people with Parkinson's?

There are several organizations that provide education and resources to care partners and loved ones of people with Parkinson's. For instance, the Caregiver Action Network (CAN), the Family Caregiver Alliance (FCA) and the Well Spouse Association (WSA), exist to support care partners to people living with various diseases, including PD.

The Parkinson's Foundation and other PD organizations provide 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.

### **For more information:**

*Download our fact sheets "Secondary Caregiving" and "Adding Family, Friends & Volunteers to Your Caregiving" at [Parkinson.org/FactSheets](http://Parkinson.org/FactSheets).*

*View our Parkinson's Expert Briefing webinars: "Caring for a Person with Late Stage Parkinson's," "Caregiving and Parkinson's: Laying the Groundwork for the Road Ahead" and "Coping Skills for Parkinson's Care Partners" at [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings).*

*Request a copy of our resource book *Caring and Coping* at [Parkinson.org/Books](http://Parkinson.org/Books). You can also request more information by calling 800-4PD-INFO.*

## CHAPTER FOUR

# Parkinson's Research: The Future

## DRUG DISCOVERY & DEVELOPMENT

### Are there any new drugs on the horizon for Parkinson's?

Research into new treatments for Parkinson's is part of the fight against this disease. There are always several promising new pharmaceutical compounds "in the pipeline" of discovery or development. New surgical approaches and gene therapies for Parkinson's are also currently being tested. Unfortunately, it takes a very long time for new therapies to go through the testing and approval process, and not all novel treatments prove successful.

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

The route from the laboratory to the medicine cabinet is long and complicated. In the US, the Food and Drug Administration (FDA) carefully oversees the development, testing, labeling and marketing of all pharmaceutical products.

Medications start with development in a laboratory. If a compound appears to be promising, it is then tested in animals to determine its effectiveness and safety. Only after a new medication passes all tests of animal safety, may a study sponsor apply to begin human studies, called clinical trials. Carefully designed, large-scale trials involving hundreds of people are then conducted to measure the effectiveness of a PD drug.

**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



An essential aspect of clinical trial design is the process of randomization. Participants are randomly assigned to receive either the medication being tested or a placebo (a non-active substance designed to look like the medication). Called a double blind study, neither the investigator conducting the trial nor the participant is allowed to know if the medication is real or placebo until the study is completed. This way, both the investigator and the person with PD are blinded as to the treatment assignment, which is the only way to ensure an unbiased evaluation of a drug.

Sometimes, the FDA requires more extensive drug testing than the manufacturer anticipated, which can delay the process by years. For people who live with Parkinson's, the pace of new advances in treatment is never fast enough. But safety is a top priority, and the FDA's painstaking efforts to ensure that a new treatment is effective and safe are justified.

*NIH Clinical Research Trials and You, found at [www.nih.gov](http://www.nih.gov), is an online resource to help people learn more about clinical trials, why they matter and how to participate.*

## What is neuroprotection?

Neuroprotection is the term used to describe treatment that may slow down, stop or reverse the progression of a brain disease by repairing brain cells and preventing them from being lost, or encouraging new ones to grow. Although researchers are attempting to develop neuroprotective agents for Parkinson's disease, no such therapy is currently proven to be clinically effective.

Selegiline and rasagiline have been studied for neuroprotective effects but the evidence to date has not been conclusive. Some people with PD have used over-the-counter antioxidant vitamins, such as vitamin C, with the goal of slowing the progression of PD. Recent studies of coenzyme Q10 and creatine conducted by the National Institutes of Health (NIH) found low likelihood that the substances delay the progression of Parkinson's. There is also interest in the potential of exercise to be neuroprotective for PD. Researchers are studying forms of exercise (dance, running, walking) to learn more.

Scientists hope to make progress toward neuroprotection as they learn more about the causes of cell death in PD.

*For information on neuroprotection trials that are enrolling participants, visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov).*

## PLAYING A PART IN RESEARCH

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

Depending on symptoms and general health, a person with Parkinson's and his or her family members without Parkinson's should think about getting involved in clinical research. Researchers need volunteers to help solve the unanswered questions about Parkinson's and to develop new treatments. All of the drugs currently used for treating Parkinson's are available only because other people volunteered to help researchers develop them.

Clinical research in Parkinson's disease takes many forms. A drug trial is designed to test new treatments, and will require participants to follow a careful protocol and make several visits to the study center. The trials of new surgical techniques for PD are even more complicated, with extensive pre-operative screening and testing, as well as long term follow-up. Others, such as genetic studies, require only a single visit during which the researchers collect information and obtain a blood sample. All of these types of research allow the discovery of new ideas and information, and advance our understanding of Parkinson's.

In the majority of trials, the 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 PD in routine clinical practice. Participating in clinical trials provides people with Parkinson's with the opportunity to receive excellent care while helping to bring drugs to the market more quickly.



While clinical study participation is important, individuals should make an informed decision by educating themselves first and asking the right questions of trial coordinators. Participants in clinical research are carefully protected from harm by FDA protocol, research ethics and careful monitoring by an Institutional Review Board (IRB) at each study site. An IRB is a committee of physicians, statisticians, researchers, advocates and others. The IRB ensures that a trial is ethical, the rights of participants are protected, and medical information is safe-guarded. All trials in the US must be approved by an IRB before they can begin to recruit participants. A person who is interested in participating in research should speak to his or her neurologist.

*For more information, request a copy of our educational booklet *Getting Involved in Parkinson's Research*, a guide to making a decision about research participation at [Parkinson.org/Books](https://www.parkinson.org/Books).*

*You can also request more information by calling 800-4PD-INFO.*

### **Can I donate my brain to research?**

Studying the post-mortem brain provides scientists with the opportunity to better understand Parkinson's. People with Parkinson's, and sometimes individuals without the disease, can choose to donate their brains to Parkinson's research.

Brain donation is a lasting contribution to science. Yet, for some people it may bring up many difficult questions and concerns.

Additionally, finding the right donation program is not always easy. There are several programs that accept donations from people with Parkinson's, but each has different requirements regarding eligibility and participation.

If a person with Parkinson's decides that brain donation is the right decision, it is best for him or her to contact the closest brain donation program to ask more questions. A list of local brain donation programs may be available from an individual's treating neurologist. Call the Parkinson's Foundation Helpline at 800-4PD-INFO for a list of organizations that accept brain tissue and their program information.

*For more information, download our fact sheet "Brain Donation" at [Parkinson.org/FactSheets](https://www.parkinson.org/FactSheets).*

*You can also request more information by calling 800-4PD-INFO.*

## Are there other ways to get involved?

In addition to participating in trials and considering brain donation, some people with Parkinson's are passionate about advocating for PD research. These individuals may educate the community about clinical studies or work to improve the development of new therapies. Others may work on a local or national level to advocate for funding of PD research.

The Parkinson's Foundation Parkinson's Advocates in Research (PAIR) program is a network of over 300 research advocates from 40 states (as of 2016) who work to bring educated consumer voices to important issues in Parkinson's therapy development. This growing network is actively collaborating with scientists, government agencies and private industry to change the role that people with Parkinson's play in the design and implementation of PD research and programs.

All of our research advocates have participated in a three-day training program, called the Learning Institute, which offers course-work focusing on the science of Parkinson's and strategies for influencing research decision-making. Research advocates continue to grow their advocacy knowledge and connections through continuing education opportunities and tools provided by the foundation.

*If you would like to learn more about this program or if you would like to speak with us about partnering with a research advocate at your institution, clinical study or support group, please visit [Parkinson.org/PAIR](http://Parkinson.org/PAIR).*

## FINDING THE CURE

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

Many scientists believe that the cure for Parkinson's will come from a deeper understanding of what causes the disease. What is the reason that dopamine neurons begin to degenerate and die? If the cause of the neurodegeneration can be identified, perhaps a specific treatment can be developed to slow, stop or reverse its process.

Future treatment strategies may include the delivery of substances or genetic material directly to the brain. They may involve replacing neurons. However, these techniques are in the earliest stages of development.

For people living with Parkinson's disease and their families, the progress is always too slow. But there are reasons to be optimistic. It is anticipated that many scientific advances will be translated into benefits for people with Parkinson's, and so the hope for a cure is linked with true promise and great optimism.

#### **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. A wealth of information about Parkinson's and about our activities and resources is available on our website, [Parkinson.org](http://Parkinson.org).

#### **YOUR FEEDBACK MATTERS!**

We'd like to know what you think of our publications and programs. Please take a few moments to fill out our online feedback form. Your answers will be used to improve our resources and will benefit people with Parkinson's, caregivers, families and others in the Parkinson's community. Thank you for your help.

**ONLINE FORM:**     [Parkinson.org/Feedback](http://Parkinson.org/Feedback)

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The Parkinson's Foundation is proud to provide this booklet and other educational materials at no cost to people around the globe. If you found this book helpful, please consider a gift so that we may continue to fight Parkinson's on all fronts: funding innovative research, providing support services and offering educational materials such as this publication. Thank you for your support.

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