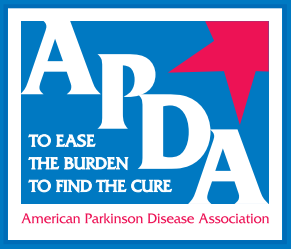

Parkinson's Disease HANDBOOK

135 Parkinson Avenue
Staten Island NY 10305
(800) 223-2732
Fax: (718) 981-4399
apda@apdaparkinson.org
www.apdaparkinson.org

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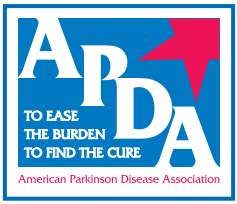


Parkinson's Disease HANDBOOK

American Parkinson Disease Association

CONTRIBUTORS

Grateful appreciation to the following who contributed to the writing of the Parkinson's Disease Handbook:

David G. Standaert, MD, PhD
John N. Whitaker Professor and Chair of Neurology
University of Alabama at Birmingham, School of Medicine
Chair, APDA Scientific Advisory Board

Marie Hélène Saint-Hilaire, MD, FRCP(C)
Associate Professor of Neurology
Boston University School of Medicine

Cathi A. Thomas, RN, MS, CNRN
Assistant Clinical Professor of Neurology
Program Director, Parkinson's Disease and Movement Disorders Center, Boston University Medical Campus
Coordinator, American Parkinson Disease Association Information & Referral Center at BUMC

Joan and Ross Collard

TABLE OF CONTENTS

VISION, MISSION, AND HISTORY

Vision | Ease the Burden – Find the Cure

Mission | To provide information, education, and support to all impacted by Parkinson's disease and to fund scientific research into the causes, prevention, treatments, and ultimately the cure.

The American Parkinson Disease Association (APDA) was founded in 1961 with the dual purpose to *Ease the Burden – Find the Cure* for Parkinson's disease by funding research, patient services, and education, and by striving to elevate public awareness of the disease. As the country's largest Parkinson's grassroots organization, APDA aims to *Ease the Burden* for the more than 1 million Americans with Parkinson's disease and their families through a nationwide network of Chapters, Information and Referral (I&R) Centers, and support groups. APDA pursues its efforts to *Find the Cure* by funding Centers for Advanced Research and awarding grants to fund the most promising research toward discovering the cause(s) and finding the cure for Parkinson's disease.

EASE THE BURDEN

APDA's nationwide network provides information and referral, education and support programs, health and wellness activities, and events to facilitate a better quality of life for the Parkinson's community and elevates public awareness about the disease. It is this grassroots structure that distinguishes APDA from other organizations serving people with Parkinson's disease.

FIND THE CURE

APDA is committed to scientific research and has been a funding partner in most major Parkinson's disease scientific breakthroughs.

HISTORY

APDA was founded more than 50 years ago, when Sophia Esposito Maestrone sought a charitable beneficiary to honor her mother Elena's commitment to philanthropy. She chose Parkinson's disease after meeting Ada I. Hursch, who was living with Parkinson's disease, leading a support group, and helping others who were suffering. In 1961, the Espositos established the Ada I. Hursch Parkinson Disease Foundation. One year later, the national organization was rededicated as the American Parkinson Disease Association.

Since that time, APDA has made an enormous impact, funding research and assisting those living every day with this chronic and disabling disease.

A LETTER TO THE READER

The American Parkinson Disease Association (APDA) is here to provide you with the necessary information and resources to better manage Parkinson's disease (PD). If you or someone close to you has been diagnosed with PD, you may feel overwhelmed. This handbook has been designed to help by providing valuable information about PD, including common symptoms, available treatments for disease management, practical tips on caring for someone with PD, and research currently underway in PD. In addition, resources that may be of help to you are provided at the end of this handbook.

As you read through this handbook, keep in mind that PD affects each person differently, so don't worry if you come across information that does not apply to you or your loved one's current situation. This handbook is intended to provide information for all of those affected by PD.

In dealing with PD, your partnership with your neurologist is extremely valuable. It is important to consult with a qualified physician you trust about the course of PD management that is best for you. The information in this handbook should better prepare you to talk to your physician and the additional healthcare providers with whom you will work. Managing any challenge is easier when working with a team, and PD is no exception. Ideally, you will be collaborating with a group of healthcare professionals with expertise in PD to better manage your care. This handbook will introduce you to many of the possible members of your healthcare team.

Your personal support team is also extremely valuable when living with PD. Maintaining your current networks of support (family, friends, groups you belong to) is crucial but also consider branching out to find others who can support your care. This handbook will provide information about resources and support services that are available to help you remain active and maintain important social connections as well as build new ones.

APDA has a dual mission to Ease the Burden – Find the Cure. To accomplish this, APDA funds important research and provides education and support to individuals living with PD, their family members, and the community at large. In addition to reading this handbook, visit APDA's website at **www.apdaparkinson.org** for more information and also consider contacting an APDA Information and Referral Coordinator who provides services in your community. APDA is here to help you take a more active role in the successful management of PD. As President of APDA, I want to welcome you to the Association and its many resources. The American Parkinson Disease Association wants you to look to the future with hope and optimism.

Sincerely,

Leslie A. Chambers
President and CEO
American Parkinson Disease Association

CHAPTER 1 | WHAT IS PARKINSON'S DISEASE?

So what exactly is Parkinson's disease (PD)? PD is a type of **movement disorder** that can affect the ability to perform common, daily activities. Although PD is associated with a wide range of symptoms, there are features of PD that most people with the condition will experience. These symptoms are typically divided into those that affect movement (**motor symptoms**) and those that do not (**non-motor symptoms**).

The most common motor symptoms of PD are **tremor** (a form of rhythmic shaking), stiffness or **rigidity** of the muscles, and slowness of movement (called **bradykinesia**). A person with PD may also have trouble with posture, balance, coordination, and walking. Common non-motor symptoms of PD include sleep problems, constipation, anxiety, depression, and fatigue, among others. You will learn about the motor and non-motor symptoms of PD in greater detail in the next chapter.

It is important to note that, although there are common symptoms of PD, they can vary greatly from person to person. Moreover, how these symptoms change over time and whether other symptoms of PD emerge differ from person to person. Most people who develop the symptoms of PD do so sometime after the age of 50, but PD can affect younger persons as well. There are an estimated 1 million Americans living with PD and more than 10 million people worldwide.

HOW PD AFFECTS THE BRAIN

What makes PD distinctive from other movement disorders is that cell loss occurs in a very specific region of the brain called the **substantia nigra** (sub-STAN-she-uh NYE-gruh). The nerve cells, or **neurons**, in this region actually appear dark under a microscope (*substantia nigra* is Latin for "black substance").

Those dark neurons produce a specific type of **neurotransmitter** (a chemical messenger that allows neurons to communicate) called **dopamine**. The neurotransmitter dopamine helps to regulate movement. This loss of dopamine is the reason that many treatments for PD are intended to increase dopamine levels in

the brain. Treatment for PD will be explained in more detail in Chapter 4.

In addition to decreases in dopamine and the cells that make dopamine, you might also read or hear about **alpha-synuclein** (AL-fa-sin-NUKE-lee-un). We do not yet know what this protein does in the healthy brain, but in PD it clumps up in what are called **Lewy** (LOO-ee) **bodies**. Researchers believe that alpha-synuclein build-up contributes to the cause of PD and that it may be possible to develop new treatments based on this idea. Future research will hopefully tell us more about this protein.

THEORIES ABOUT CAUSE

The cause of PD is still unknown, although there is some evidence for the role of genetics, environmental factors, or a combination of both. It is also possible that there may be more than one cause of PD. Scientists generally believe that both genetics and environment interact to cause PD in most people who have it. Currently, there is an enormous amount of research directed at producing more answers about what causes PD and how it might be prevented or cured. When physicians diagnose PD, they often describe it as **idiopathic** (ID-ee-oh-PATH-ik). This simply means that the cause of PD is not known.

Genetic Factors

Scientists estimate that less than 10% of cases of PD are primarily due to genetic causes. The most common genetic effect that triggers PD is mutation in a gene called LRRK2. The LRRK2 defect is particularly frequent in families of North African or Jewish descent. Mutations in alpha-synuclein have also been found to trigger PD, but these are quite rare. In most cases of PD, no primary genetic cause can be found.

Environmental Factors

Certain environmental factors, such as significant exposure to pesticides or certain heavy metals and repeated head injuries, can increase risk of PD. Most people do not have a clear environmental cause for their PD, and because many years can

pass between exposure to an environmental factor and the appearance of PD symptoms, the connection is often difficult to establish. However, it seems likely that environmental factors do influence the development of PD, perhaps particularly in people who *also* have a genetic susceptibility.

Other Risk Factors

There are other things that put an individual at higher risk for developing PD. The main risk factor is age, because PD is more common in older adults (>50 years of age). Men also have a higher risk of PD than women. PD often seems to affect Caucasians more than African Americans or Asians. The actual links between any of these factors and PD are not completely understood.

Now that you know a bit more about what PD actually is, the following chapter will provide greater detail about what to expect in terms of symptoms.

TIPS FOR UNDERSTANDING MORE ABOUT PD

Every day we learn more about the causes of and treatments for PD as results from new research emerge. APDA currently funds a diverse research portfolio and supports Centers for Advanced Research across the country. To learn more about APDA's research programs, visit **www.apdaparkinson.org/research**.

This chapter describes the most common symptoms of PD. Remember once again that, although there are typical symptoms of PD, these can vary greatly from individual to individual—both in terms of their intensity and how they progress. Motor symptoms generally involve movement, while non-motor symptoms do not.

MOTOR AND RELATED SYMPTOMS OF PD

There are five primary motor symptoms of PD: tremor, rigidity, bradykinesia (slow movement), postural instability (balance problems), and walking/gait problems. Observing one or more of these symptoms is the main way that physicians diagnose PD.

Tremor

Characteristically occurring at rest, the classic slow, rhythmic tremor of PD typically starts in one hand, foot, or leg and eventually affects both sides of the body. The **resting tremor** of PD can also occur in the jaw, chin, mouth, or tongue. This tremor may become less apparent or even disappear during a purposeful movement, but a so-called **action tremor** (a tremor with intentional movement) may also be a feature of PD. In addition, some people with PD can experience a feeling of **internal tremor**, which is not necessarily noticeable to others.

Because resting tremor is a hallmark of PD, its presence (at least in some form) is a strong clue for the diagnosis of idiopathic PD. However, there are other types of tremors that can be easily mistaken for the tremor of PD. Therefore, it is crucial to consult with a physician who has specialized training in neurology and/or movement disorders to assess the quality of any recurrent or persistent tremor. Conversely, when a person experiences other common symptoms of PD but *does not* exhibit the characteristic tremor, other diagnoses may be possible, including other movement disorders. Disorders that have some of the motor signs and symptoms of idiopathic PD are called **Parkinsonian syndromes** or Parkinsonism.

Rigidity
Rigidity refers to a tightness or stiffness of the limbs or torso. Rigidity, especially in the early stages of PD, may be wrongly attributed to arthritis or orthopedic problems, such as a rotator cuff injury.

Bradykinesia
Greek for "slow movement," bradykinesia is a frequent symptom of PD and related movement disorders. In addition to a general slowness of movement, the bradykinesia of PD is typically demonstrated by a reduced or mask-like expression of the face (hypomimia), a decreased blink rate of the eyes, and problems with fine motor coordination (for example, difficulties buttoning a shirt). Having trouble turning over in bed and slow, small handwriting (micrographia) are other signs of bradykinesia.

Postural Instability
More pronounced in the later stages of PD, postural instability includes the inability to maintain a steady, upright posture or to prevent a fall. Such balance problems in PD are associated with a tendency to list or fall backward (retropulsion); in fact, a light push can cause the individual with PD to continue stepping backward or to even fall down. If postural instability is an obvious symptom, especially in the early stages of illness, physicians will consider other diagnoses from the various Parkinsonian syndromes.

Walking or Gait Difficulties
Bradykinesia and postural instability both contribute to walking, or gait, difficulties in PD, particularly as the disease progresses. A common, early symptom of PD is a decrease in the natural swing of one or both arms when walking. Later, steps may become slow and small, and a shuffling gait (festination) may appear. Gait problems in PD can also include a tendency to propel forward with rapid, short steps (propulsion). People with advanced PD may experience episodes of freezing, in which the feet appear to be glued to the floor.

Vocal Symptoms

In addition to the core motor symptoms of PD, changes in the voice are commonly experienced in PD. Generally, these are believed to be at least partly due to bradykinesia. In PD, the voice may become softer, or it may start off strong and then fade away. There may be a loss of the normal variation in volume and emotion in the voice, so that the individual may speak in a monotone. In more advanced PD, speaking may become rapid, with the words crowded together, or stuttering may occur.

> Symptoms of PD can vary greatly from individual to individual—both in terms of their intensity and how they progress.

NON-MOTOR SYMPTOMS OF PD

Because PD is a type of movement disorder, the associated non-motor symptoms can be overlooked. However, there are several common symptoms of PD that do not primarily involve movement.

Disturbances in the Sense of Smell

A reduced sensitivity to odors (**hyposmia**) or a loss of smell (**anosmia**) is often an early symptom of PD. In fact, hyposmia and anosmia may be experienced months or even years before the traditional motor symptoms of PD emerge.

Sleep Problems

Sleep problems are commonly experienced by people with PD. The inability to fall asleep, or **primary insomnia**, is less common than the inability to stay asleep, or **secondary insomnia**. Some people with PD disrupt the normal sleep-wake cycle by taking catnaps throughout the day; doing this may lead to an inability to sleep at night. Other individuals with PD have vivid dreams, although these are more typically due to side effects of

medications for PD. Less commonly, people with PD may talk or thrash in their sleep, particularly during the rapid eye movement (REM) sleep stage (**REM sleep behavior disorder**).

Depression and Anxiety

Depression is a fairly common non-motor symptom of PD. It can range in severity and may improve with PD treatment, anti-depressant medications, and "talking therapy" or psychotherapy, such as **cognitive behavioral therapy (CBT)**. Group or family therapy may also help alleviate depression. Anxiety also occurs in PD and, like depression, can be mild or severe. In some cases, anxiety may require medication. As with depression, psychotherapy such as CBT can help to address anxiety.

Fatigue

Fatigue is a complex symptom of PD that is not fully understood. It is known, however, that fatigue is significantly associated with depression and sleep disorders.

Mental Processes

Particularly in more advanced PD or in older people with PD, problems with thinking, word finding, and judgment are common. If these symptoms occur in the early stages of illness, however, they may be symptoms of a related disorder (eg, dementia with Lewy bodies) rather than idiopathic PD. Many individuals report difficulties in multitasking and organizing daily activities. Confusion may also be a side effect of some PD medications.

Weight Loss

Loss of weight is a common symptom of PD, particularly in the later stages of the illness. If weight loss is significant and unintended, your physician should perform an examination to exclude other medical causes of weight loss. While there can be a great deal of weight loss with PD, it will typically level off. There are different causes of weight loss in patients with PD, including decreased appetite (**anorexia**), swallowing difficulties, gastrointestinal problems such as chronic constipation, or depression. The constant motion of an advanced resting tremor

or involuntary movements may burn many calories and can also be the cause of weight loss.

Gastrointestinal Issues

Disturbances of the gastrointestinal system are common in PD. Constipation, in particular, occurs frequently because PD may slow the automatic movement of the digestive system; however, side effects of medications may also contribute to constipation. Reduced swallowing and associated drooling or collection of saliva are often seen in PD. Nausea and vomiting occur occasionally in untreated PD, but more often these symptoms are related to medication side effects. Nausea and vomiting are most frequent when treatment for PD first begins.

Lightheadedness

Separate from the balance problems of postural instability but contributing to gait problems, lightheadedness or a faint feeling occurs often in PD. This symptom is related to the body's inability to quickly regulate blood pressure, particularly when sitting up from a lying position or standing from a sitting position. This phenomenon is known as **orthostatic or postural hypotension**. Feelings of lightheadedness may also be increased by certain medications for PD. When severe, lightheadedness may cause black-outs or fainting.

Urinary Issues

Urinary frequency (the need to urinate often) and **urinary urgency** (the feeling that one must urinate right away, even if the bladder is not full) are other possible symptoms of PD. These symptoms occur because the normal reflex mechanisms that control the bladder are disrupted. Urinary problems may be worse at night, when a person is lying flat. There may also be problems with initiating a urine stream (**urinary hesitancy**), slowness of urination, and overfill of the bladder. It should be noted that urinary symptoms in older men specifically may be caused by an age-related enlargement of the prostate gland and not PD.

Sexual Concerns

Changes in sexual desire, or **libido**, is another non-motor symptom of PD that is often under-recognized. Sexual desire may be reduced in some cases because of complex psychological issues. In other cases, a reduced libido can be a direct effect of PD. Treatment with PD drugs frequently improves sexual desire and, in some cases, even increases it to a troublesome level. In men, the inability to achieve or maintain an erection (**impotence**) can occur; however, impotence may also be related to other age-related changes in the body or other conditions.

Sweating

Excessive sweating is a relatively common sign of PD, particularly if the disease is untreated. It happens most often in the upper body.

Melanoma

Individuals with PD may have an increased risk of melanoma, a serious type of skin cancer. As a result, people with PD should undergo annual skin examinations with a dermatologist. If you notice any troubling skin lesions, be sure to talk to your physician about them.

If you or someone you know is demonstrating any of these symptoms, consider consulting a physician who specializes in movement disorders. If you have already been diagnosed with PD, talk to your physician about symptoms as they arise to determine the best ongoing treatment.

The next chapter will provide more information on how PD is diagnosed.

PRIMARY MOTOR SYMPTOMS OF PD

- Tremor
- Rigidity
- Bradykinesia (slowness of movement)
- Postural instability (balance problems)*
- Walking or gait difficulties*

**May be more apparent in the later stages of illness*

CHAPTER 3 | DIAGNOSIS

PD is usually diagnosed clinically, meaning that a physician looks for the presence or absence of the possible symptoms of PD by interviewing the patient and performing a detailed neurologic examination.

While there is presently no definitive test for PD, it can often be identified by a **general neurologist**, who is trained to diagnose and treat neurologic disorders. To avoid misdiagnosis, consultation with a movement disorder specialist is recommended. A **movement disorder specialist** is a physician who has undergone additional, subspecialty training in the diagnosis and treatment of movement disorders, such as PD, after training in general neurology.

WHAT TO EXPECT AT THE FIRST PHYSICIAN VISIT

When you or someone you know first visits a physician for the evaluation of possible PD symptoms, it is helpful to know what to expect. During the first visit, the physician should:

- Take a complete and careful medical history
- Take your blood pressure while you sit and stand
- Assess your thinking (or **cognitive**) skills
- Examine your facial expression
- Look for tremor in your face, hands, arms, or legs
- Examine whether there is stiffness in your arms, legs, torso, or shoulders
- Determine whether you can get up easily from a chair, especially without using your arms
- Examine your walking pattern
- Assess your balance as you stand

Typically, a trained physician will only consider the diagnosis of PD if the person being examined has at least two of the core motor symptoms of PD, including tremor, the characteristic bradykinesia (slowness of movement), or rigidity. At the end of

your visit, the physician should discuss with you why you may or may not have PD and the level of certainty about the diagnosis. This determination is based on your medical history and examination at this visit.

TOOLS TO AID DIAGNOSIS

In addition to taking a history and performing a detailed neurologic examination, physicians sometimes use brain imaging to help support a particular diagnosis. However, these studies have their limitations in the diagnosis of PD and are typically used only in select patients. Brain imaging is *not* routinely performed by neurologists or movement disorder specialists when they are considering the diagnosis of PD, especially if the person's symptoms strongly suggest to the physician that idiopathic PD is the correct diagnosis.

Rather, use of imaging is most helpful when the diagnosis is uncertain, or when physicians are looking for changes in the brain that are more typical of one of several Parkinsonian syndromes (and not idiopathic PD) and other conditions that can mimic PD. Imaging studies to evaluate PD and Parkinsonian syndromes include **magnetic resonance imaging (MRI)**, which examines the structure of the brain, and **DaTscan**, an imaging test approved by the Food and Drug Administration (FDA) to detect the dopamine function in the brain. A DaTscan may help differentiate idiopathic PD from other disorders that cause tremor or other Parkinsonian syndromes. Most physicians' offices will have access to MRI; however, DaTscan imaging may only be available at larger hospitals or medical centers.

Other imaging studies that can be done, but that are not used routinely in the clinic, include **functional MRI (fMRI)**, a specialized form of brain imaging that examines brain function, and **positron emission tomography (PET)**, which can measure certain brain functions. Although PET and fMRI imaging can be used as tools to assist with the diagnosis of PD and Parkinsonian syndromes, they are largely reserved for research purposes at this point.

If a person's symptoms and neurologic examination are only suggestive of PD or if the diagnosis is otherwise in doubt, the physician may, nevertheless, prescribe a medication intended for PD to provide additional information. In the case of idiopathic PD, there is typically a positive, predictable response to PD medication; in the case of some related Parkinsonian syndromes, the response to medication may not be particularly robust, or it may be absent entirely (the next chapter will talk more about PD treatments). A DaTscan may be particularly useful for the refinement of a diagnosis if a person with PD symptoms does not respond to the usual PD medications.

Unfortunately, there are no standard biological tests for PD, such as a blood test. However, researchers are actively trying to find "biological markers" in blood and other bodily fluids that could help confirm the diagnosis of PD.

THE HEALTHCARE PROVIDER TEAM

In addition to a general neurologist or movement disorder specialist, you or someone you know with PD symptoms or a PD diagnosis may encounter several other healthcare providers. In fact, a team approach to the management of PD usually provides the best outcomes in the long term.

Key members of the PD healthcare team include nurses, physician assistants, physical therapists, dieticians, social workers, occupational therapists, neuropsychologists, and speech therapists, among others. All of these individuals can play important roles in the successful management of PD, although their input may not be immediate or necessary throughout the entire course of PD. Also, a regular relationship with a primary care physician (a family physician or general internist) is important to assess, maintain, and monitor your general physical health.

HOW TO PREPARE FOR YOUR FIRST PHYSICIAN VISIT

- Bring your complete medical and surgical history. If you have medical records from other physicians, particularly if these records are extensive, have copies of them forwarded to the neurologist or movement disorder specialist before your visit. Be sure to include results from any brain imaging studies that you may have undergone.
- Bring a complete list of medications (prescription and over-the-counter) you take. Also include any nutritional or vitamin supplements that you take regularly. Because some medications can produce or exacerbate the symptoms of PD, it is crucial to provide a complete list of medications and supplements that you are currently taking or have taken within the last year or so.
- Know your family medical history, particularly with respect to any first-degree relatives with tremor or other symptoms resembling those of PD.
- Be prepared to share any history related to alcohol use, tobacco use, or the use of illicit drugs.
- Be prepared to discuss your living situation, social support system, and employment (if relevant), and how you are coping with your symptoms, both physically and mentally.
- Because a first-time office visit can feel overwhelming, particularly one at a larger medical center, bring along a trusted family member or friend for support and assistance. Among other benefits, this person is extremely useful for helping you gather and remember information. Ask this person to take notes during your visit. Sometimes the physician may allow you to record the conversation.

IF IT'S NOT IDIOPATHIC PD, WHAT COULD IT BE?

There are several other conditions that might produce symptoms that can be mistaken for PD. Here are some possibilities:

- Medication side effects: Certain drugs can produce or exacerbate the symptoms of PD.
- Essential, or familial, tremor: This is a relatively common and benign cause of recurrent tremor and is often confused with the tremor of idiopathic PD. A general neurologist or movement disorder specialist is the best physician to help differentiate between these two conditions.
- A Parkinsonian syndrome: The symptoms of several neurologic conditions are similar to those of idiopathic PD, but they are often managed differently and often do not respond to the typical medications for PD.

Remember: Only a general neurologist or movement disorder specialist can tell you with reasonable certainty if you have idiopathic PD. If for some reason you are not comfortable with the results of your first physician visit, getting a second opinion from another general neurologist or movement disorder specialist is always an option. It is important that you feel comfortable with your physician to ensure the best possible outcome for you.

Once you or your loved one has a diagnosis of PD, it is time to discuss treatment options with your physician. The next chapter will discuss current treatments for PD.

Once you are diagnosed with PD, your focus should be on improving your symptoms and maintaining an active and positive lifestyle. Although there is currently no cure for PD, it is possible to successfully manage symptoms through healthy choices, medications, and, in select cases, medical procedures.

LIVING WITH PD

Living with PD involves addressing symptoms through:

- Lifestyle, including regular exercise and a healthy diet
- Medications and other treatments
- Bradykinesia (slowness of movement)
- A supportive social network
- A strong partnership with your healthcare team

DAILY LIVING

Exercise and Daily Activity

In the management of PD, your lifestyle is one of the first things on which you will want to focus. Starting or continuing a schedule of regular exercise can make a big difference in your mobility, both in the short and long term. In fact, several research studies have shown that regular exercise routines of walking, strength training, or Tai Chi can help to maintain, or even improve, mobility, balance, and coordination in people with PD. People with PD also report the physical (and mental) benefits of swimming, cycling, dancing, and even non-contact boxing. Whatever you enjoy to stay mobile is the best activity for you, as you will be more likely to stay committed to it. Generally speaking, in the case of PD, the more active you are, the more active you'll stay.

If you did not exercise regularly before your diagnosis, or if you are unsure about your level of fitness or stamina, talk to your primary care physician first. It's important to have your overall

health, and specifically your cardiac status, evaluated before starting any new exercise regimen. Also, a physical therapist is a great resource for finding out what your body can tolerate and what you can do safely on a regular basis. Your primary care physician or neurologist can provide you with referral to a physical therapist, if necessary. Regardless of your level of fitness, an early evaluation by a physical therapist is likely to be very valuable. Among other benefits, a physical therapist can help you individualize your exercise regimen to suit your needs and capabilities.

The APDA Rehab Resource Center at Boston University was established to help people with PD access information on exercise recommendations. This center provides callers an opportunity to speak with a licensed physical therapist who can answer questions about exercise and resources in the caller's area. Find out more at **www.bu.edu/neurorehab/resource-center**.

In addition to physical therapists, occupational therapists can help people with PD better manage their daily activities, particularly as the disease progresses. Occupational therapists can help make the most of a person's mobility with any number of daily activities—whether it's writing, typing, cooking, driving, bathing, dressing, or grooming. Modifications for work and to the workplace environment also fall under the expertise of the occupational therapist.

A speech and language pathologist will evaluate and treat changes in voice volume and speech patterns. The Lee Silverman Voice Treatment (LSVT) program, an evidence-based therapy to increase loudness, is provided by many practitioners. Speech and language pathologists also address swallowing difficulties. **Dysphagia** (dis-FAY-jyah), which is difficulty moving food from the mouth to the esophagus, requires careful assessment and treatment to avoid complications due to swallowing problems.

Diet

There is no one diet that is recommended for PD, but healthy eating in general is always a good choice. For example, eating several servings of fruits and vegetables a day increases fiber intake and can help alleviate constipation, in addition to promoting general health. Also, drinking plenty of water or other non-alcoholic and caffeine-free beverages ensures adequate hydration and may reduce the likelihood of muscle cramping.

Registered dieticians are great resources for reviewing your diet and making recommendations about healthy foods and daily calorie counts. A balanced diet should ensure that you get the recommended daily supply of vitamins to maintain your overall health. There is currently no evidence that extra vitamins or nutritional supplements are useful in the management of PD, but research is actively ongoing in this area. Depending on your bone health, however, your primary care physician may recommend vitamin D and/or calcium supplements.

There has been much attention given to the use of **antioxidants** to prevent or slow the progression of PD. Antioxidants are substances that remove toxic **free radicals**, which are produced by cells in the body during injury or stress. In cells, these free radicals promote something called **oxidative stress**, a condition associated with cell loss and aging. The overproduction of free radicals and oxidative stress may also contribute to the development of PD. Antioxidants, such as vitamin E and coenzyme Q10, remove free radicals to reduce the effects of oxidative stress. However, a large study published in the early 1990s showed that supplemental vitamin E did not slow the progression of PD; in fact, people with PD who took supplemental vitamin E fared worse than those who did not. As a result, supplemental vitamin E is not recommended for people with PD. In addition, another recently published study showed that coenzyme Q10 did not provide any clinical benefit to people with PD over a placebo (sugar pill). Nevertheless, antioxidants obtained through your diet may still be beneficial, and research in this area continues.

AN EYE ON ANTIOXIDANTS

The following "super foods" contain high levels of antioxidants and other important vitamins:

- Grapes
- Blue and red berries
- Nuts
- Dark green vegetables, such as spinach, broccoli, and kale
- Sweet potatoes and carrots
- Tea, especially green tea
- Whole grains
- Beans, such as soybeans, lentils, and black-eyed peas
- Fish, such as tuna, salmon, and sardines

Depending on your prescribed medications, you may need to adjust your diet further. Your physician and pharmacist will tell you if your medications need to be taken at certain times of day or with or without certain foods or beverages. In some people with PD, dietary protein may affect the absorption of **levodopa** (LEE-voe-DOPE-ah), a common treatment for PD. In addition, if you are taking medications that include levodopa, you may need to adjust the time that you take iron supplements (if you take them), because these supplements can affect the absorption of levodopa from the gastrointestinal tract

MEDICATIONS FOR THE MOTOR SYMPTOMS OF PD

Although there is no cure for PD, there are several classes of medications available for the successful treatment of motor symptoms throughout the course of the disease. Be sure to talk with your general neurologist or movement disorder specialist

about your most troubling symptoms and your goals for medical therapy. Some medications work better than others for specific symptoms of PD. Make sure you provide your physicians with a complete list of medications (both prescription and over-the-counter) and any vitamin or nutritional supplements that you may be taking.

The benefits of medications can only be obtained if you have access to them and take them as directed. Some medications for PD are available in generic forms or through special programs, so that they are more affordable. Some medications for PD are available in extended release or other forms, which allows for less frequent or easier dosing. Talk to your general neurologist or movement disorder specialist about your situation as well as any preferences for obtaining and taking your medications. Nurses, physician assistants, and pharmacists are also extremely valuable sources of information regarding all of your medications, including how they should be taken, their side effects, and how they may interact with other medications.

Carbidopa-levodopa **(Parcopa®, Rytary®, Sinemet®, Sinemet CR®)**
A longstanding mainstay of PD treatment, the combination medication of **carbidopa-levodopa** (CAR-bee-DOPE-ah-LEE-voe-DOPE-ah) is intended to increase brain levels of dopamine, which are deficient in people with PD. Levodopa, which is converted to dopamine in the brain, reduces tremor, stiffness, and slow movement in people with idiopathic PD. Carbidopa prevents levodopa from being broken down in the body before it reaches the brain. Therefore, the addition of carbidopa allows levodopa to get into the brain more efficiently. Available in various strengths, carbidopa-levodopa is typically started at a low dosage. The dosage is then increased over time as tolerated and until optimal therapeutic benefits are experienced. Carbidopa-levodopa is available in the United States as an immediate-release tablet (Sinemet®), a controlled-release tablet (Sinemet CR®), an extended-release capsule (Rytary®), and an orally disintegrating tablet (Parcopa®).

Occasionally, people taking carbidopa-levodopa may observe a harmless darkening of the saliva, sweat, or urine. More concerning side effects include sleepiness (which can be sudden), impulse control behaviors, hallucinations, and confusion. In more advanced PD, levodopa may cause fragmented or jerky movements of the limbs or torso (called motor fluctuations or **dyskinesias** [dis-keh-NEE-zhee-ahs]) at the peak effect of the medication. In addition, unpredictable swings from mobility to immobility (**"on-off" phenomenon**) can be seen with levodopa treatment in advanced disease.

Carbidopa-levodopa Infusion **(Duopa™)**
A new form of carbidopa-levodopa (Duopa™) was approved by the FDA in 2015. It is intended for people with more advanced disease, whose symptoms are no longer responding well to oral carbidopa-levodopa. Instead of taking a pill, people with PD can receive carbidopa-levodopa in a gel form through an infusion pump. The pump delivers the medication directly into the small intestine through a surgically placed tube. The advantage of a continuous infusion of the carbidopa-levodopa is less immobility or "off" time from levodopa.

The side effects of the carbidopa-levodopa infusion are similar to those of oral carbidopa-levodopa.

Dopamine Agonists: Apomorphine **(Apokyn®),** ***Pramipexole*** **(Mirapex®, Mirapex ER®),** ***Ropinirole*** **(Requip®, Requip XL®),** ***Rotigotine*** **(Neupro®)**
Dopamine agonists (AG-oh-nists) are a little different from carbidopa-levodopa in that, instead of increasing dopamine levels in the brain, they mimic the activity of dopamine. Sometimes they are given alone in the early stages of PD and sometimes along with carbidopa-levodopa or other PD medications. Dopamine agonists are available in immediate-release (Mirapex®, Requip®) or extended-release (Mirapex ER®, Requip XL®) formulations. One of the dopamine agonists (Neupro®) is available as a skin patch. As with carbidopa-levodopa, dopamine agonists are

typically begun at a low dosage and titrated upward as tolerated and until optimal therapeutic benefits are experienced.

Apokyn® (apomorphine hydrochloride injection) is a dopamine agonist, but its effect is very quick and brief. A so-called rescue medication, Apokyn® is reserved for people with advanced PD who have trouble with severe immobility or "off" periods during levodopa therapy. Apokyn® is given as an under-the-skin injection, often by a care partner.

The side effects of dopamine agonists are similar to those of carbidopa-levodopa. Apokyn® in particular can cause severe nausea, so it must be given with a medication that reduces or prevents nausea. Remember that it is important to review with your prescribing physician or pharmacist the side effects of all of your medications, both prescription and over-the-counter, and how they may interact with your other medications or alcohol.

***COMT Inhibitors: Entacapone* (Comtan®), *Tolcapone* (Tasmar®)**
COMT inhibitors are sometimes used with carbidopa-levodopa. Like carbidopa, they prevent the breakdown of levodopa before it reaches the brain. The result is that a more reliable supply of levodopa enters the brain, where it can be converted to dopamine. COMT inhibitors are typically prescribed to treat frequent "off" times with levodopa therapy. The COMT inhibitor entacapone (Comtan®) is available as a combination pill with carbidopa-levodopa (Stalevo®).

Sometimes COMT inhibitors can increase the side effects associated with levodopa therapy. Other common side effects of COMT inhibitors are abdominal pain, constipation, and blood in the urine. Regular blood tests for liver function are required with the use of tolcapone (Tasmar®).

***Selective MAO-B Inhibitors: Rasagiline* (Azilect®), *Selegiline* (Eldepryl®, Zelapar®)**

Selective MAO-B inhibitors block the MAO-B enzyme in the brain, which breaks down dopamine. This is another way to increase dopamine levels in the brain. MAO-B inhibitors can be used alone or with other PD medications. When used early as a single treatment, MAO-B inhibitors may delay the need for carbidopa-levodopa therapy. Selective MAO-B inhibitors may be prescribed to complement carbidopa-levodopa therapy, particularly if individuals experience "wearing-off" symptoms while taking levodopa. The selective MAO-B inhibitors for PD are available as a swallowed pill (Azilect®, Eldepryl®) or an orally disintegrating tablet (Zelapar®).

Side effects of selective MAO-B inhibitors include mild nausea, dry mouth, lightheadedness, constipation, and, occasionally, hallucinations and confusion. Previous restrictions on the intake of foods containing tyramine (for example, aged cheeses, red wine, and draft beers) with selective MAO-B inhibitors have been relaxed by the FDA. However, MAO-B inhibitors can interact with other medications, such as antidepressants, nasal decongestants, and narcotic pain medications. Your physician or pharmacist can help you to understand these potential interactions.

***Anticholinergics: Benztropine* (Cogentin®), *Trihexyphenidyl* (Artane®)**

Anticholinergics (AN-tie-COAL-an-ER-jicks) are often used for the management of PD as complementary medications to other, standard PD therapies. Anticholinergics are frequently prescribed to reduce the characteristic tremor of PD or to ease the problems associated with the wearing off of levodopa therapy.

Common side effects of anticholinergics include confusion, hallucinations, constipation, dry mouth, and urinary problems. As a result, the use of anticholinergics is typically limited to younger people with PD (under the age of 70). These anticholinergics should also be avoided in combination with antihistamines, certain psychiatric drugs, and alcohol.

Other Medications

Also used to prevent or treat influenza, **amantadine** (ah-MAN-ta-deen) (Symmetrel®) has been observed to ease the tremor of PD as well as muscle rigidity. It is typically used as a complementary medication to other standard therapies for PD. In addition, it is used to decrease dyskinesia or involuntary movements caused by levodopa. Common side effects include lightheadedness, dry mouth, constipation, vivid dreams, and swelling of the ankles. It may also interact with or enhance the side effects of anticholinergics and levodopa therapy. Amantadine is available in pill and syrup forms.

Propranolol (pro-PRAN-ah-loll) (Inderal®, Inderal LA®) is a long-standing, commonly used cardiac medication that is also prescribed in the management of PD to reduce the associated tremor of the disease. Because this drug slows the heart rate, it may cause or exacerbate lightheadedness (orthostatic hypotension), which may lead to fainting. Propranolol is available as a swallowed pill in immediate-release (Inderal®) and long-acting (Inderal LA®) forms.

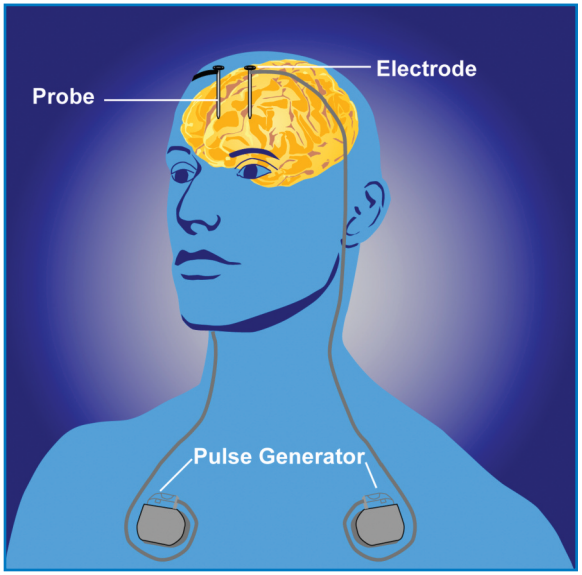
The recently FDA-approved drug **droxidopa** (DROCKS-ee-DOPE-ah) (Northera™) is specifically indicated to treat the orthostatic hypotension of neurologic diseases like PD. It should be used with caution in people with cardiac disease, as it may aggravate certain cardiac conditions. Common side effects include headache, dizziness, nausea, hypertension, fatigue, fever, and confusion. In addition, high dosages of carbidopa-levodopa may interfere with the activity of droxidopa. Other medications used to treat orthostatic hypotension are **fludrocortisone** (FLUE-droh-KOR-ta-sone) (Florinef®) and **midodrine** (MID-row-deen) (ProAmatine®).

SURGERY

Deep Brain Stimulation

Deep brain stimulation (DBS) is a neurosurgical procedure reserved for people with advanced PD, specifically people who have tried a number of different medication regimens for their motor symptoms. DBS is designed to reduce the "on-off" motor fluctuations of levodopa therapy by allowing for a reduction in the dosage of levodopa therapy. DBS involves the implantation of permanent, thin electrodes into selected deep parts of the brain.

Two permanent battery-operated pulse generators, much like cardiac pacemakers, are then implanted under the skin of the chest or abdomen. The pulse generators are connected to the stimulator electrodes via wires, which are tunneled underneath the skin of the scalp and neck. Working continuously, the pulse generators are designed to suppress the motor symptoms of PD, thereby allowing for a reduction in medication (although most people who undergo DBS still need to take some PD medications).



National Institute of Mental Health. *Brain stimulation therapies.* 2015. www.nimh.nih.gov/health/topics/brain-stimulation-therapies/brain-stimulation-therapies.shtml. Accessed September 10, 2015.

Adjustments to the pulse generators are individualized to realize the best effect of DBS. The DBS procedure is associated with a small chance of infection, stroke, bleeding, or complications associated with anesthesia.

ALTERNATIVE/COMPLEMENTARY THERAPIES FOR MOTOR SYMPTOMS

While you may hear about other nonconventional treatments for PD, such as massage, acupuncture, and acupressure, so far the use of these kinds of treatments in the management of PD is not supported by scientific evidence. Nevertheless, you may find them beneficial in addition to **evidence-based medicines** approved for PD. You should discuss the possible pros and cons of these options with one or more members of your healthcare team.

TREATMENTS FOR NON-MOTOR SYMPTOMS OF PD

People with PD commonly experience non-motor symptoms, including depression, anxiety, sleep problems, or other difficulties. If you are experiencing any of these problems, be sure to discuss them with one or more members of your healthcare team. Additional therapies or medications (beyond those that treat the motor symptoms of PD) may be useful. However, never underestimate the role of a social support network. Family members and friends can play pivotal roles in helping you to maintain your healthcare regimen and to keep a positive outlook.

Research in PD is ongoing, and new treatments may be on the way. The final chapter discusses the latest in research, potential treatments on the horizon, and clinical trials. Also provided are additional resources for people with PD and their families.

CONSIDER JOINING A SUPPORT GROUP

Participating in a support group is a wonderful way to receive practical information and education about living with PD. More importantly, members receive the support of others who truly understand the illness. APDA has a long history of developing and maintaining support groups in communities throughout the United States. Some groups are organized and operated by group members, and many of these groups receive guidance and support from social workers, nurses, psychologists, and other healthcare professionals. Please visit **www.apdaparkinson.org/resources-support/local-resources** to find support groups in your area.

There is a great deal of ongoing research to better understand the cause of PD, confirm the clinical diagnosis of PD, and find new therapies for the symptoms of PD. In addition, investigations are underway to identify treatments that will delay the progression of PD and ultimately cure it.

Along with new formulations or new combinations of existing medications, several novel medications are under late-phase study for the treatment of PD. These include new dopamine agonists, MAO-B inhibitors, and other drugs that modify neurotransmitter levels in the brain. It is also hoped that some drugs under investigation will protect nerve cells and prevent their loss. Furthermore, researchers are investigating whether drugs used for other conditions, such as epilepsy or diabetes, may have therapeutic benefits in people with PD as well. Finally, DBS is continuously being studied and refined to determine the best part of the brain to be targeted for stimulation.

DO YOU WANT TO ENROLL IN A CLINICAL TRIAL?

Clinical trials also contribute to the further treatment and understanding of PD and potentially provide access to the newest therapies. For more information and to learn if a clinical trial may be right for you, consult with your healthcare team. The following websites provide information about ongoing clinical trials and how you or someone you know can enroll:

- The NIH Registry of Clinical Trials
  www.clinicaltrials.gov
- Parkinson's Disease Biomarkers Program
  pdbp.ninds.nih.gov
- CenterWatch
  www.centerwatch.com/clinical-trials/listings
- Fox Trial Finder
  www.foxtrialfinder.org

CARING FOR THOSE WITH PD

Remember that PD not only affects the person who has been diagnosed with this disease; it also affects family members, friends, and co-workers. People caring for those with PD also need support. If you are a care partner or you know someone who is, it is important to remember that the care partner must pay attention to his or her own physical and mental health. Many times, care partners overlook their own health, because so much time is spent caring for the person with PD.

If you are a care partner, consider contacting a care partner support group. Access to these groups is available through many local APDA Chapters as well as Information and Referral Centers (**www.apdaparkinson.org/resources-support/local-resources**). These groups can provide up-to-date information on PD, treatment strategies, and tips to assist care partners. Through these groups, care partners can also meet others who have had similar experiences in caring for an individual with PD. Your state's Department of Aging may also provide information, resources, and support for PD care partners.

LIVING TO YOUR FULLEST POTENTIAL

At APDA, we want you to achieve the best quality of life right now and to live to your fullest potential. It is possible to have an active and fulfilling life with PD. We hope that this handbook has been a helpful first step for you or someone you know with PD to achieve a life filled with meaning, hope, and optimism. Please contact APDA for further information and use APDA's additional resources at **www.apdaparkinson.org**.

RESOURCES

APDA is here to help you to live with PD. The APDA network provides information and referrals, education and support programs, health and wellness activities, and events to facilitate a better quality of life for the PD community. Search the APDA website by state to connect to an Information and Referral Center or APDA Chapter in your community at:

www.apdaparkinson.org/resources-support/local-resources

APDA also provides information and referrals that are specific to young onset PD. Generally speaking, people younger than 50 years of age who are diagnosed with PD are considered to have young onset PD. To speak with someone about young onset PD, contact:

(800) 223-2732 or young@apdaparkinson.org

APDA Rehab Resource Center at Boston University was established to help people with PD access information on exercise recommendations. This center provides callers an opportunity to speak with a licensed physical therapist who can answer questions about exercise and resources in the caller's area. Find out more at:

www.bu.edu/neurorehab/resource-center
(888) 606-1688

For information about services provided through the Veterans Health Administration for military veterans with PD, call:

(800) 223-2732

Finally, APDA provides free online publications on a variety of topics at:

www.apdaparkinson.org/resources-support/download-publications

GLOSSARY

Action tremor: a tremor that occurs with intentional movement

Alpha-synuclein: a protein that builds up in certain nerve cells in certain brain regions of people with PD and related conditions

Amantadine: medication used to prevent or treat influenza that is also used to ease the tremor and rigidity of PD

Anorexia: decreased appetite

Anosmia: loss of the sense of smell

Anticholinergics: a class of drugs often used for the management of PD, typically as complementary medications to other, standard PD therapies; used to reduce the tremor of PD or ease the problems associated with the wearing off of levodopa therapy

Antioxidants: substances found in certain foods and supplements that can remove toxic free radicals from the body

Bradykinesia: slowness of movement; a common motor symptom of PD

Carbidopa-levodopa: a combination medication commonly used to treat PD; intended to increase dopamine levels in the brain

Care partner: a person, such as a close family member or friend, who supports an individual with a chronic medical condition

Clinical trials: studies conducted in humans, often involving a drug or some other type of treatment

Cognitive: pertains to thought processes, such as memory, attention, concentration, and judgment

Cognitive behavioral therapy (CBT): a form of psychotherapy used to treat depression that focuses on challenging unrealistic thoughts and replacing them with more realistic ones

COMT inhibitors: drugs that block catechol-O-methyltransferase (COMT), an enzyme that breaks down dopamine and levodopa; used in PD to prevent the breakdown of levodopa therapy before it reaches the brain

DaTscan: FDA-approved imaging test used to detect dopamine function in the brain; can help differentiate idiopathic PD from other disorders that cause tremor or other Parkinsonian syndromes

Deep brain stimulation (DBS): involves the use of embedded pulse generators to suppress the motor symptoms of PD, thereby allowing for a reduction in medication; surgical option for people with advanced PD who have tried a number of different medication regimens for their motor symptoms

Dopamine: a brain chemical (neurotransmitter) that enables movement; brain levels of dopamine fall in certain brain regions in people with PD

Dopamine agonists: drugs that mimic the action of dopamine

Droxidopa: FDA-approved drug used to treat the orthostatic hypotension of neurologic diseases like PD

Dyskinesias: fragmented or jerky movements of the limbs or torso; often apparent at peak times of levodopa therapy in more advanced PD

Dysphagia: difficulty moving food from the mouth to the esophagus

Evidence-based medicine: use of the best scientific evidence from clinical research to optimize clinical decision-making

Festination: a shuffling manner of walking associated with small steps and slowness of movement (bradykinesia)

Fludrocortisone: medication used to treat orthostatic hypotension

GLOSSARY (continued)

Free radicals: toxic substances that are produced by cells in the body during injury or stress

Functional magnetic resonance imaging (fMRI): imaging technique that allows physicians to see the structure and function of the brain

Gait: pattern of walking

General neurologist: a physician who is trained to diagnose and treat neurologic disorders

Hypomimia: a reduced or mask-like expression of the face

Hyposmia: reduced sensitivity to odors

Idiopathic: of unknown cause

Impotence: the inability to maintain or achieve an erection

Internal tremor: sensation of vibration inside the body

Lewy bodies: clumps of protein (alpha-synuclein) found in the nerve cells in certain brain regions of people with PD and related conditions

Libido: sexual desire

Magnetic resonance imaging (MRI): imaging technique that allows physicians to see the structure of the brain

Micrographia: slow, small handwriting

Midodrine: medication used to treat orthostatic hypotension

Motor symptoms: symptoms that primarily involve movement

Movement disorder: a neurological condition that affects movement

Movement disorder specialist: a physician, typically a neurologist, who has undergone further training to diagnose and treat movement disorders

Neurons: nerve cells, which form the structure for interconnected, intercommunicating networks in the brain

Neurotransmitter: a brain chemical that allows neurons to communicate with one another

Non-motor symptoms: symptoms that do not primarily involve movement

"On-off" phenomenon: unpredictable swings from mobility to immobility; usually seen in people with more advanced PD who are treated with levodopa therapy

Orthostatic or postural hypotension: the body's inability to quickly regulate blood pressure, particularly when sitting from a lying position or standing from a sitting position

Oxidative stress: a destructive condition in which free radicals damage cells; associated with cell loss and aging

Parkinsonian syndromes: movement disorders that are not idiopathic PD but have some overlapping symptoms, such as rigidity and slowness of movement (bradykinesia)

Positron emission tomography (PET): imaging technique that can measure certain brain functions

Primary insomnia: the inability to fall asleep

Propranolol: a longstanding, commonly used cardiac medication that is also prescribed in the management of PD to reduce the associated tremor of the disease

Propulsion: a type of gait problem associated with propelling forward and rapid, short steps

GLOSSARY (continued)

Rapid eye movement (REM) sleep behavior disorder: a particular type of sleep disorder that may be associated with talking or thrashing in one's sleep

Resting tremor: a tremor that occurs when still; a hallmark of PD

Retropulsion: the tendency to fall backward

Rigidity: stiffness of the muscles

Secondary insomnia: the inability to stay asleep

Selective MAO-B inhibitors: drugs that selectively block the enzyme monoamine oxidase B (MAO-B) in the brain; MAO-B breaks down dopamine

Substantia nigra: meaning "black substance" in Latin, a region in the base of the brain that contains dopamine-producing neurons, which appear dark under a microscope; people with PD experience cell loss in this region

Tai Chi: a form of exercise developed in ancient China that can help with posture and balance

Tremor: a form of rhythmic shaking

Urinary frequency: the need to urinate often

Urinary hesitancy: difficulty initiating a urine stream

Urinary urgency: the feeling that one must urinate right away, even if the bladder is not full

NOTES