

**Parkinson's Disease:
What You
and
Your Family
Should Know**

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Chapter 1

Parkinson's Disease's: A Basic Understanding

Parkinson's disease (PD) is a complex disorder of the brain. Because it is a disease that affects the brain, it is classified as a **neurological disorder** – neurological means “related to the nerves” – and the doctors who specialize in diseases that affect the brain are called neurologists.

Parkinson's disease is primarily diagnosed clinically – your doctor figures out you have Parkinson's by watching you move and asking you about your experience. PD is classified as a **movement disorder**, meaning it is a neurological disorder that affects how you move. Many university medical centers and some hospitals employ specially-trained neurologists called **movement disorders specialists**, who are neurologists with extra training to better understand diseases like Parkinson's. A movement disorders specialist is very good at diagnosing and treating Parkinson's.

The first person to observe people with Parkinson's and document the key features of the disease was a nineteenth century British physician named James Parkinson. He first described the condition in 1817 when he wrote a paper titled *Essay on the Shaking Palsy*. In his essay, he described the major symptoms of the disease that would later bear his name. Scientists have since pursued greater understanding of the disease, including its range of symptoms, distribution among the population, and treatment options.

Who Gets Parkinson's Disease?

An estimated one million people in the United States, and four to six million worldwide, have PD. It affects more people than multiple sclerosis, amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), muscular dystrophy, and myasthenia gravis combined.

PD affects about 15 per 1,000 Americans over the age of 55 years. While the illness is less common at younger ages, it does occur (see chapter 6, “Special Concerns of Persons with Young-Onset Parkinson's Disease”). The exact number of cases in younger people is difficult to determine, but it is estimated that five percent of all persons with Parkinson's are diagnosed before age 40 and 15 percent are diagnosed before age 50.

Many people live with symptoms of Parkinson's for several years before being diagnosed. Often people in early stages of the illness assume that their symptoms are the result of normal aging or other health problems, such as arthritis. Early Parkinson's symptoms are subtle and may even come and go. Frequently it is the spouse or other relative who first notices slight problems with a loved one's movements.

Parkinson's disease seems to affect men slightly more than it affects women. Some studies have shown that African-Americans and Asians are less likely than Caucasians to develop PD, although the reasons for this are not clear. Otherwise, the disease knows no social, ethnic, economic, or geographic boundaries.

If you have PD, it is important to see a specialist: a neurologist or—even better—a movement disorders specialist (a neurologist who has completed specialized training in PD and movement disorders, usually through a one- to two-year fellowship). Research from the National Parkinson Foundation's Parkinson's Outcomes Project, the largest-ever clinical study of Parkinson's, has shown that every year, neurologist care saves the lives of more than 4,600 people with Parkinson's in the U.S.

What Is Parkinson's Disease?

Parkinson's disease is a **progressive, neurodegenerative disorder**. It is classified as a movement disorder because of the tremors, slowing, and stiffening movements it can cause, but its symptoms are diverse (see “What Are the Symptoms of Parkinson's Disease?” on page 5) and usually develop slowly over time.

Dr. Parkinson's 1817 essay, and our understanding of the disease from the earliest days until the 1970s, focused on the major clinical symptoms of PD that emerge from how the disease impacts the **dopamine** system. Dopamine is a **neurotransmitter**, or chemical messenger in the brain, that regulates movement and emotions. When dopamine-producing neurons in a part of the brain called the **substantia nigra**, meaning “black substance” (for how it looks when you cut the brain open!) are affected by the disease, Parkinson's symptoms – like tremors and slow movement – appear.

Today, there are several competing theories for how Parkinson's develops. While lack of dopamine plays a clear role in Parkinson's, to the best of our knowledge, most PD is what we call a **synucleinopathy**. This means it is a disease associated with a protein in the human brain called **alpha synuclein**. However, we don't know what role alpha synuclein plays in Parkinson's.

Some scientists are looking at whether misfolded alpha synuclein slowly diffuses throughout the brain. Other scientists think that there is something special about the cells that produce dopamine, making those cells more vulnerable than others. Other theories include problems with mitochondria, the power plants of the cell, or with processes of waste removal in the cells.

PD is the most common form of **parkinsonism**, the label for a group of disorders with similar features. PD is called primary parkinsonism or **idiopathic** Parkinson's disease. Idiopathic is a term used to describe a disorder for which the cause is unknown.

What Causes Parkinson's Disease?

Dopamine is the chemical messenger responsible for transmitting signals between the substantia nigra and the next “relay station” of the brain, allowing smooth, coordinated function of the body's muscles and movement. This is how we move, without really thinking about it. The loss of the dopamine-producing neurons in the substantia nigra results in difficulty with movement (see the next section on the symptoms of PD). The cause of this cell death or damage is not known, but research continues to yield important new clues. Lack of dopamine in people with Parkinson's was first described in the 1960s. Soon after, dopamine-replacement therapy (i.e., **levodopa**) became—and remains—the gold standard treatment.

Treating the dopamine system is critical to helping people with Parkinson's deal with their symptoms. However, the better we address the dopamine system, the more clearly we can see how the synucleinopathy impacts other systems. Dopamine is not the only neurotransmitter to be affected by Parkinson's. The disease process also disrupts other brain chemicals like serotonin, norepinephrine, and **acetylcholine**, and this causes changes in mood, behavior, and cognition. For example, researchers are studying the impact of PD on the **cholinergic system**. This system is also involved in controlling movement, including gait (walking) and balance, as well as memory and sleep. The cholinergic system is affected after the dopamine system, and we have no good treatments for its dysfunction.

Researchers are exploring the role of genetic factors in the development of PD. While several genes are known to cause Parkinson's, the majority of cases do not yet have any genetic link or family history of PD. Genetic factors continue to be a major area of focus for research into the cause of Parkinson's disease.

In all but a tiny fraction of people with PD, there is a combination of your own unique biology and your environmental exposures that results in your developing PD. Your unique biology includes your genes, the amount you exercise, and other factors that are unique to you. Your environmental exposures include all the chemicals that you encounter in your life, germs and viruses, and other things. Researchers have shown that people developed Parkinson's-like symptoms from the 1918 Spanish flu, and other scientists are currently looking at the microbiome of the gut for influence on Parkinson's.

Upon receiving the diagnosis, sometimes people wonder if the onset of Parkinson's symptoms could be linked to some traumatic event such as an accident, surgery, or extreme emotional distress. There is no evidence to support that concern. Although a significant trauma might trigger symptoms earlier than they would otherwise occur, this should not be confused with actually causing PD.

Parkinson's is not contagious: it cannot be passed from one person to another by casual or intimate contact.

What Are the Main Motor Symptoms of Parkinson's Disease?

The four main **motor symptoms** of PD are:

- Shaking or **tremor**
- Slowness of movement, called **bradykinesia**
- Stiffness or **rigidity** of the arms, legs and trunk
- Trouble with balance, also called **postural instability**

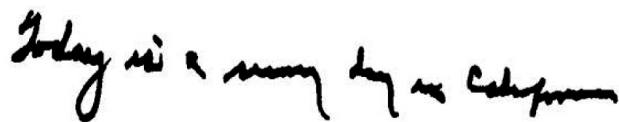
Symptoms of Parkinson's disease vary from person to person and change over time. But a Parkinson's diagnosis will only be considered when two of the four main motor symptoms are present over a period of time. Here are the four main motor symptoms of PD:

- **Tremor** is present in approximately 70% of people with PD. People with a tremor in a hand or foot while at rest, which is called a resting tremor, usually have a more slowly progressing course of illness than those without tremor. Parkinson's tremor has a characteristic appearance, taking the form of a "pill-rolling" movement between the thumb and forefinger (imagine holding a pill between your thumb and pointer finger and continuously rolling it around). Tremor usually begins in one hand, although sometimes a foot or the jaw is affected first. A tremor is most obvious when the affected limb is at rest or when a person is under stress. In three out of four people with PD, the tremor affects only one side of the body, especially during early stages of the disease. Tremor usually disappears during sleep or lessens with intentional movement, such as reaching out a shake hands or gripping a steering wheel. Fatigue, stress, or intense emotions may temporarily worsen the tremor.
- **Bradykinesia**, a profound slowness of movement and loss of spontaneous, automatic movement, is often the most disabling symptom of Parkinson's disease. Bradykinesia is particularly frustrating because it can interfere with daily activities and is often unpredictable. One moment you can move easily, while in the next moment, you may need help.
- **Rigidity**, while seldom the main symptom early in your Parkinson's, is experienced as a stiffness of the arms or legs beyond what would result from normal aging or arthritic changes. Rigidity of the trunk may also be present. Some patients refer to rigidity as "tightness" in their limbs.
- **Postural instability**, or impaired balance, causes people to develop a forward or backward lean and to fall easily. This symptom is not usually present with diagnosis, but it's one of the most common and troublesome symptoms that happens later on.

Other Symptoms of Parkinson's Disease

The movement challenges described above can have a broad impact. Other characteristic features of PD include the following:

- Decreased automatic reflexes, such as blinking
- **"Freezing,"** or the feeling of being "stuck in place" when attempting to walk
- Loss of facial expression due to rigidity of facial muscles, called **hypomimia** or facial masking
- Low voice volume or muffled speech, called **dysarthria**
- Reduced arm swing or slight foot drag on the affected side
- Small, cramped handwriting, called **micrographia**
- Tendency to fall backwards, called **retropulsion**
- Walking with a series of quick, small, shuffling steps, as if in a hurry, called **festination**



Today is a sunny day in California

As the symptoms described above predominantly involve movement, they are called **motor symptoms**. These are what people generally picture when they think of Parkinson's disease. However, most people develop other health problems related to PD. These symptoms are diverse but are collectively known as **non-motor symptoms**.

There are many symptoms of Parkinson's, but remember: no one individual develops all the symptoms! While you will likely have many things in common, your specific symptoms, disease progression, and experience will be different than anyone else with Parkinson's you meet.

It is important to be aware of the variety of non-motor symptoms and the fact that they can be connected to your Parkinson's. In fact, research shows that some non-motor symptoms, such as loss of sense of smell, sleep disorders, and depression, frequently appear long before the motor symptoms of PD. Only looking back after diagnosis do people recognize the connection.

Non-motor symptoms are common and can be more troublesome than motor symptoms. If you notice any of these issues, discuss them with your health care team, so together you can develop a plan to manage them.

Non-motor symptoms can include the following:

- Cognitive changes, such as problems with focused attention and planning, slowness of thought, and language and memory difficulties
- Constipation and early satiety (a feeling of fullness after eating small amounts)
- Drop in blood pressure when standing, called **neurogenic orthostatic hypotension**
- Fatigue
- Hallucinations and delusions (more of a problem later in the disease progression)
- Impulse control disorders, such as binge eating or excessive shopping or gambling (usually a side effect of medications)
- Increase in dandruff and oily skin
- Loss of sense of smell
- Mood disorders, such as depression, anxiety, and irritability, beyond the normal responses to life stress
- Pain
- Sleep disorders, such as insomnia, excessive daytime sleepiness, REM sleep behavior disorder, and vivid dreams
- Urinary urgency, frequency, and incontinence
- Vision problems

The nature of PD varies greatly from one person to another. It is possible that you will have to adapt your lifestyle to accommodate the difficulties that PD presents. For example, it may take longer or require more concentration to accomplish a task once considered "automatic." However, when these changes happen and how you deal with them will be different for everyone.

How Is Parkinson's Disease Diagnosed?

Making an accurate diagnosis in the early stages of Parkinson's can be difficult, because there is no single diagnostic test that can confirm whether or not a person has PD. Your doctor will take a detailed medical history, perform a physical examination, watch you move, and ask about your experience.

Diagnosis can be complicated by the fact that some of the symptoms of PD can be caused by other conditions. A variety of blood tests and a brain scan might be done to rule out conditions that have similar symptoms. When a diagnosis of PD is in question, it is best to see a movement disorders specialist, a neurologist who has completed specialized training in PD and other movement disorders.

Usually, you need to have two of the four primary symptoms (tremor, bradykinesia, rigidity, and postural instability) for your physician to consider a diagnosis of PD. A trial of Parkinson's medication may be given to see if it improves symptoms; these medications are discussed in Chapter 3.

Atypical Parkinsonism

Over time, approximately 15% of people originally diagnosed with Parkinson's disease begin to show signs of having what is sometimes called "**atypical**" parkinsonism. This is also referred to as "**Parkinson's-plus**" syndromes. In these cases, the person has the symptoms of PD, but the course of the disease is not typical; for example, symptoms may progress more rapidly or are less responsive to antiparkinson medications than is normal for PD. Someone who cannot tolerate levodopa, or who does not obtain benefit after a sufficient trial on that medication, may have an atypical parkinsonism. Following are descriptions of some of the most common Parkinson's-plus disorders. It is important to remember that many people will not exhibit the cardinal symptoms necessary for a diagnosis of a specific disorder and will simply be labeled "parkinsonism."

- **Progressive supranuclear palsy (PSP)** is one of the more common forms of atypical parkinsonism and progresses more rapidly than PD. Symptoms usually begin in the early 60s. Common early symptoms include forgetfulness, personality changes, and loss of balance while walking that results in unexplained falls. Difficulty moving the eyes, particularly to look up, is a hallmark feature. Individuals with PSP may have some response to dopaminergic treatment but may require higher doses than people with Parkinson's disease.
- **Multiple system atrophy (MSA)** (also called Shy-Drager syndrome) is the term for a group of disorders in which one or more systems in the body stop working. In MSA, the autonomic nervous system is often severely affected early in the course of the disease. Symptoms include bladder problems resulting in urgency, hesitancy, or incontinence and orthostatic hypotension. For men, the earliest sign may be loss

of erectile function. Other symptoms that may develop include impaired speech, difficulties with breathing and swallowing, and inability to sweat. Like the other parkinsonisms, MSA symptoms either don't respond very much or don't respond at all to Parkinson's medications.

- **Drug-induced parkinsonism** can be difficult to distinguish from Parkinson's, though the tremors and postural instability may be less severe. It is usually the side effect of drugs that affect dopamine levels in the brain, such as antipsychotics, some calcium channel blockers, and stimulants like amphetamines and cocaine. If the affected person stops taking the drug(s), symptoms usually subside over time, but may take as long as 18 months to do so.

There are some medications that are not safe for people with Parkinson's. Go to www.awareincare.org or call the NPF Helpline at 800-4PD-INFO (473-4636) to order your free **Aware in Care** kit. This includes a wallet-size card with a list of safe and unsafe medications.

- **Vascular parkinsonism** is usually caused by clotting in the brain from multiple small strokes. People with vascular parkinsonism tend to have more problems with gait than tremor and have more problems in the lower body. The disorder progresses very slowly in comparison to other types of parkinsonism. People might report an abrupt onset of symptoms or step-wise deterioration (symptoms get worse then plateau for a while). Symptoms in vascular parkinsonism may or may not respond to levodopa.
- **Dementia with Lewy bodies (DLB)** is second only to Alzheimer's as the most common cause of dementia in the elderly. It causes progressive intellectual and functional deterioration. In addition to the signs and symptoms of Parkinson's disease, people with DLB tend to have frequent changes in thinking ability, level of attention or alertness, and visual hallucinations. They usually do not have a tremor or have only a slight tremor. The Parkinsonian symptoms may or may not respond to levodopa. If signs of dementia appear before or within one year of motor symptoms, a diagnosis of DLB should be considered.

For resources and information about dementia with Lewy bodies, contact the National Parkinson Foundation Helpline at 800-4PD-INFO (473-4636) or helpline@parkinson.org.

- **Corticobasilar degeneration (CBD)** is the least common atypical parkinsonism. It usually develops after age 60. Symptoms include a loss of function on one side of the body, involuntary and jerky movements of a limb and speech problems. It may become difficult or impossible to use the affected limb, although there is no weakness or sensory loss. The individual may feel as if the limb is not under his/her voluntary control. There is no specific treatment at this time for CBD.

Conditions that Can Mimic PD

- **Essential tremor (ET)** is fairly common in the elderly population, but it may begin at any age. It is relatively easy to distinguish from the tremor typical of PD. While PD tremor usually affects one hand while in a resting position, ET usually affects both hands equally, and often involves a head tremor and tremulous quality of the voice. Essential tremor is also known as familial tremor and is inherited in 30 to 50% of people that have it.
- **Normal pressure hydrocephalus (NPH)** mainly affects people 60 years of age and older. With NPH, the fluid inside the brain does not properly drain, resulting in difficulty with walking, slowed thinking, and loss of bladder control. While the symptoms of NPH are similar to those of PD, NPH is an entirely different condition. NPH can usually be diagnosed by specialized brain scans, lumbar puncture (also called a spinal tap), and physical examination. The treatment often involves surgery to place a shunt, which helps to drain the excess fluid from the brain.

Chapter 2

Medical and Surgical Treatment Options

The diagnosis of Parkinson's disease does not automatically require that medication be taken. Currently there is no medication that has been proven to slow or halt the progression of PD. You should carefully discuss treatment goals with your health care team and work together to determine when the symptoms interfere with daily activity to the point that medications are necessary. Some symptoms of PD respond better to medication than others. Possible long-term side effects of Parkinson's drugs must also be considered.

There are several scales used in research and by health care providers to measure how severe Parkinson's is and how far it has progressed. Many clinicians use an assessment tool known as the Unified Parkinson's Disease Rating Scale (UPDRS) to help diagnosed PD, as well as to follow your progress over time. Using the UPDRS, the clinician can evaluate motor function, the patient's experience of symptoms, and performance of activities of daily living and medication side effects.

For more detailed information on Parkinson's medications, order your copy of the NPF publication ***Parkinson's Disease: Medications***. For a quick reference guide to typical PD medications (which can also be shared with your health care team), order an ***Aware in Care kit***. Both the book and the kit can be ordered for free online at www.parkinson.org/books or by calling the NPF Helpline at 800-4PD-INFO (473-4636).

Medications for Motor Symptoms

Most symptoms of Parkinson's disease are caused by the lack of dopamine within the brain. The majority of Parkinson's drugs are aimed at temporarily replenishing or mimicking dopamine, so they are often called **dopaminergic** drugs. These medications generally reduce muscle rigidity, improve speed and coordination of movement, and lessen tremor.

Dopaminergic drugs do not cure or slow the progression of PD; however, they are the most effective medications for treating the motor symptoms of PD. Dopaminergic medications includes carbidopa/levodopa, dopamine agonists, anticholinergic drugs, and amantadine.

Carbidopa/Levodopa

Levodopa was the first major breakthrough in the treatment of Parkinson's disease. The brain converts levodopa into dopamine, which is stored within the neurons (brain cells) until needed by the body for movement. Levodopa remains the single most effective agent in the management of Parkinson's symptoms. Levodopa is almost always given in combination with another medication called carbidopa. This combination ensures that as much levodopa gets to the brain as possible, with the least amount of side effects.

Carbidopa/levodopa is available in a variety of strengths and forms, including tablets that are swallowed or dissolved on the tongue, capsules, and a gel pump to the intestines. Carbidopa/levodopa tablets are available in immediate-release and slow-release forms (brand names Sinemet and Sinemet CR, respectively), as well as a dissolvable tablet that is placed under the tongue (Parcopa). One form of carbidopa/levodopa (Stalevo) is combined in a tablet with entacapone, a COMT inhibitor, which is described later in this chapter.

The dose of carbidopa/levodopa required to control symptoms varies widely from one person to another. In the early years post-diagnosis, many people experience a good response to medication. It is important to realize that this “honeymoon” period can often be achieved with relatively low doses, which may help prevent or delay the onset of side effects.

After several years of treatment with carbidopa/levodopa, some people may find that controlling symptoms becomes more difficult and requires more medication. At this point, the brain has stopped producing dopamine in any significant amount, so it must rely on dopaminergic medications. When levodopa begins to take effect, you experience periods of good symptom control (“on” time), when you can move and function well. As levodopa begins to lose its effect, you may have periods in which symptoms are suddenly much more noticeable and movement becomes more difficult (“off” time). You might even have periods in which peak medication levels produce involuntary movements (dyskinesias). When individuals experience these various states throughout the day, they are said to have **motor fluctuations**, or **“on-off” fluctuations**.

In 2015, the FDA approved two new formulations of carbidopa/levodopa for sale in the U.S., both of which are meant to help with motor fluctuations. Carbidopa/levodopa extended release (ER) capsules (Rytary) contain beads of carbidopa and levodopa that dissolve and are absorbed at different rates. Therapeutic levodopa levels are reached about an hour after taking it, similar to carbidopa/levodopa immediate release (IR), and these levodopa concentrations are maintained for 4-5 hours before declining. Clinical trials indicate that people with motor fluctuations on other oral carbidopa/levodopa products may be able to switch to these capsules and experience a reduction in “off” time. For prescribing and dosing information to share with your doctor, visit www.parkinson.org/rytary.

The other new offering is a dopamine pump (DUOPA), which provides 16 continuous hours of carbidopa and levodopa for motor symptoms. The small, portable infusion pump delivers carbidopa and levodopa directly into the small intestine. In a clinical trial, the amount of “on” time without troublesome dyskinesia was better in the pump group when compared to the placebo group (4.1 vs. 2.2 hours). One of the major drawbacks to the pump approach is the need for a percutaneous gastrojejunostomy (a small, surgically-placed feeding tube). These tubes can be the starting locations for infections and other complications.

The medication carbidopa/levodopa comes in a variety of strengths and forms.

Dopamine Agonists

Dopamine agonists (DAs) are a different class of medication used to treat the motor symptoms of PD. Dopamine agonists work differently than levodopa. While levodopa is converted in the brain into dopamine, dopamine agonists actually mimic the effects of dopamine without having to be converted. In many cases, a dopamine agonist is the first medication that will be prescribed to treat PD and, in early stages, may be the only medication needed to control the motor symptoms. As the disease progresses, a dopamine agonist may be given in combination with levodopa to help reduce the intensity of "wearing-off" and generally enhance the effects of levodopa.

Commonly prescribed dopamine agonists include ropinirole (Requip), pramexipole (Mirapex), rotigotine (Neupro), and apomorphine (Apokyn).

Like all medications, dopamine agonists can have side effects, such as drowsiness and fatigue (relatively common) and confusion/delirium (uncommon in younger patients). One possible side effect to pay special attention to is the development of impulse control disorders, including compulsive gambling or sexual behavior.

For reasons not well understood, some patients respond well to one dopamine agonist, but may not tolerate or have as good a response to another. Work with your health care team over time to discover the best combination for you.

A dopamine agonist is often the first medication prescribed to treat PD.

Amantadine

Amantadine (Symadine, Symmetrel) was initially developed in the 1960s as an antiviral medication to treat influenza. Only by coincidence was it discovered to help symptoms in PD. Amantadine often provides only mild relief, and therefore is most commonly used for early therapy. It is used in combination with levodopa to treat motor fluctuations, specifically dyskinesias.

Anticholinergic Drugs

Anticholinergics are the oldest class of medicine used to treat Parkinson's disease; they were first used in the early 1900s. These drugs affect block the effects of acetylcholine in the brain and can help restore balance between acetylcholine and dopamine. Some anticholinergics typically prescribed for PD are trihexyphenidyl HCl (Artane), bethtropine (Cogentin), and ethopropazine (Parsitan). An over-the-counter antihistamine called diphenhydramine (Benadryl) also has anticholinergic properties.

Anticholinergics are most useful in young people whose chief Parkinson's complaint is tremor. However, anticholinergics can also cause significant mental and physical side effects, including confusion, hallucinations, decreased short-term memory, dry mouth, blurry vision, and urinary retention issues, especially in older people with PD. Research from NPF's Parkinson's Outcomes Project supports the finding that cognitive slowing is a side effect of anticholinergics, so carefully discuss their use with your health care team.

COMT Inhibitors

Entacapone (Comtan) and tolcapone (Tasmar) are drugs in the class known as COMT inhibitors. When a person takes levodopa, an enzyme in the body called catechol-O-methyltransferase (COMT) converts a portion of it into a form that is useless in treating PD. By blocking COMT with medications such as tolcapone or entacapone, more levodopa is made available to enter the brain and reduce PD symptoms. These inhibiting agents are only effective when used in combination with levodopa; a medication called Stalevo combines carbidopa, levodopa, and entacapone in one pill.

MAO-B Inhibitors

Monoamine oxidase B is an enzyme that naturally breaks down several chemicals in our brain, including dopamine. Like COMT inhibitors block COMT, MAO-B inhibitors block the activity of the MAO-B enzyme, thereby blocking the breakdown of dopamine in the brain. This makes more dopamine available and reduces some of the motor symptoms of PD. MAO-B inhibitors provide modest benefit for the motor symptoms of PD. They are usually used early in the disease as monotherapy (meaning it is the only drug you take) or as an adjunct (add-on) to other medications. MAO-B inhibitors enhance the effect of levodopa.

Commonly prescribed MAO-B inhibitors include rasagiline (Azilect), selegiline (Eldepryl), and selegiline HCl (Zydis, Zelapar), which is an orally disintegrating form preferred for people with difficulty swallowing.

In addition to medications for the motor symptoms of PD, there are medications and other treatment options for many of the non-motor symptoms of Parkinson's, including depression, neurogenic orthostatic hypotension, and more. To learn more, order your free copy of ***Parkinson's Disease: Medications*** by calling the NPF Helpline at 800-4PD-INFO (473-4636) or visit www.parkinson.org/understanding-parkinsons.

Medication Advisory

There are many medications available to help treat the symptoms of Parkinson's disease and keep you functioning at a high level. Work with your health care team to find the right medication or combination of medications for you. All medications have side effects, so make sure to discuss any changes with your doctor.

Recently research has produced several new medication options, with more anticipated in the coming years.

The information here is a basic overview of Parkinson's medications. For more detailed information, order your free copy of NPF's publication *Parkinson's Disease: Medications* online at www.parkinson.org/books or by calling the toll-free NPF Helpline at 800-4PD-INFO (473-5636).

Surgical Treatments

In the early stages of PD, medications are usually enough to control the motor symptoms. As the disease progresses, and if motor fluctuations become a problem, surgical treatments may be considered. Surgery is an option only for those who, under the care of a movement disorders neurologist, have exhausted the benefits of Parkinson's medication and require additional intervention.

There are several surgeries that have been used to treat PD. Pallidotomy, thalamotomy, and subthalamotomy are all named for the part of the brain targeted during surgery. In these procedures, the brain is lesioned, meaning tissue is destroyed. **Deep brain stimulation (DBS)** is another surgical procedure used to treat PD. While none of these is a cure, pallidotomy and DBS have shown the best results in the treatment of PD. DBS differs from pallidotomy, thalamotomy, and subthalamotomy in that it does not destroy brain tissue.

Undergoing any surgical procedure is serious commitment, so you should consult with a movement disorders specialist before making any decision.

For resources and detailed information about deep brain stimulation for the treatment of PD, contact the National Parkinson Foundation Helpline at 800-4PD-INFO (473-4636) or helpline@parkinson.org.

Chapter 3

Staying Well with Parkinson's Disease

Medication and surgery are not the only approaches to managing Parkinson's. There are other actions you can take to stay well. Establishing an exercise program, eating right, getting enough sleep, and taking care of your mental and spiritual health are some of the ways that you can lead an active, fulfilling life with PD. Learning to pace yourself and prioritize goals can help you accomplish daily activities.

The information below can be used as a guide, but work with your caregivers, family, and health care team to create your own plan. Every individual is unique, and a healthy lifestyle should be approached within the framework of your personal, spiritual, and cultural beliefs.

Exercise

Parkinson's disease affects the overall quality of movement. It is not a disorder of muscle weakness, but the dopamine depletion does contribute to a loss of stamina and coordination. Not only will exercise complement your medication therapy to enhance motor function; for people with Parkinson's, exercise is medicine!

It is well-known that exercise is good for the body: it can prevent problems due to inactivity and muscle weakening; help maintain joint flexibility, muscle strength, and tone; and improve circulation to the heart and lungs. Regular exercise has been proven to have a positive effect on mood and overall sense of wellbeing, reducing stress and increasing a sense of control over your Parkinson's symptoms.

But did you know that exercise is also good for the brain? NPF-funded studies show that exercise facilitates **neuroplasticity** (brain connectivity) and might even be able to reverse executive function deficits (e.g., problems with focused attention and planning) in people with PD. Researchers are studying the type of exercise that may be most beneficial for improving cognitive function in people with PD, as well as the role of exercise in brain connectivity and repair.

People often call the NPF Helpline and ask, "What is the best type of exercise for people with Parkinson's?" First and foremost, you should find something you enjoy doing, so you will actually do it! Listed below are some general guidelines for exercising with PD:

- To help manage the symptoms of Parkinson's, your exercise program should include a few key ingredients: **flexibility/stretching exercises, aerobic activity, and resistance training or strengthening exercises.**
- **Set realistic goals.** If you are uncertain of your limits or abilities, ask your doctor to refer you to a physical therapist or exercise physiologist for evaluation and to develop an exercise program.
- Choose a time to **exercise when your medicines are working well** and you feel rested.

- **Wear loose, comfortable clothing** and shoes that provide good support.
- **Do not do or continue any exercise that causes pain.** All movement should be performed in a controlled manner to prevent injury. Avoid bouncing when performing stretches.
- **Learn to recognize when you are tired.** Strike a balance between doing too much and doing too little. If you overexerted yourself one day, take a break from the routine the following day to heal and restore your energy.
- It may be necessary to **pace yourself**, doing one part of the routine at one time of day and adding another segment later in the day.
- Remember that **it takes time to see and feel benefits** of an exercise program. Strengthening, stretching and conditioning are all most effective when done on a regular basis.

For more information on exercise for PD, visit www.parkinson.org/exercise and request your free copy of the NPF publication **Parkinson's Disease: Fitness Counts** by calling the NPF Helpline at 800-4PD-INFO (473-4636).

Nutrition

A healthy diet with plenty of water is the foundation for health, regardless of whether or not you have PD. However, for people with Parkinson's, good nutrition is even more important. For example, eating well will help keep your bones strong, decreasing the likelihood of a fracture should you fall. Healthy eating will also help you fight constipation, which is common with PD.

The United States Department of Agriculture and the Department of Health and Human Services provide these general guidelines for healthy eating:

- **Eat a variety of foods** to get the energy, protein, vitamins, minerals, and fiber you need for good health.
- **Balance the food you eat with physical activity. Maintain or improve your weight** to reduce your chances of having high blood pressure, heart disease, a stroke, certain cancers, and the most common kind of diabetes.
- **Choose a diet with plenty of grain products, vegetables, and fruits**, which provide needed vitamins, minerals, fiber, and complex carbohydrates and can help you lower your intake of fat.
- **Choose a diet low in fat, saturated fat, and cholesterol** to reduce your risk of heart attack and certain types of cancer and to help you maintain a healthy weight.
- **Choose a diet moderate in sugars.** A diet with lots of sugars has too many calories and too few nutrients for most people can contribute to tooth decay.
- **Choose a diet moderate in salt and sodium** to help reduce your risk of high blood pressure.
- **If you drink alcoholic beverages, do so in moderation.** Alcoholic beverages supply calories, but little or no nutrients. Drinking alcohol is also the cause of many health problems and accidents.

For more nutrition information specific to PD, request your free copy of the NPF publication ***Parkinson's Disease: Nutrition Matters***. Order online at www.parkinson.org/books or by calling the NPF Helpline at 800-4PD-INFO (473-4636).

Keeping a Strong Voice

Effective verbal communication – talking and listening – to family, friends, and co-workers is one of the most basic and valued activities of daily living. Even in the early stages of PD, many complain that their voices are too soft, causing people to ask them to repeat statements. Others may have a gruff, hoarse quality to the voice.

Here are some suggestions that can help you maintain good communication:

- **Take a breath before you start to speak**, and pause between phrases to take in another breath. Express your ideas in short, concise sentences.
- **Speak louder than you think is necessary**. PD causes the voice volume to be lowered, and you may not realize how soft your speech has become.
- **Encourage friends and family to ask you to speak louder** or repeat yourself if they cannot understand what you said.
- If you have trouble with your speech, **ask your health care provider to refer you to a speech-language pathologist**—this is a health care professional trained to evaluate and treat problems with speech and swallowing.

For more information, get your copy of the free NPF publication ***Parkinson's Disease: Speech and Swallowing***. Order online at www.parkinson.org/books or by calling the NPF Helpline at 800-4PD-INFO (473-4636).

Activities of Daily Living

Sometimes the challenges of living with PD interfere with basic activities once considered routine. Activities of daily living include bathing, dressing, eating, sleeping, walking, and getting from one place to another. These and other routines are what we normally do as part of our daily lives. Some people report that it takes them longer to perform self-care tasks or that they had to learn new ways of doing those tasks.

If you are having trouble accomplishing activities of daily living, ask your health care provider to refer you to an occupational therapist. This is a specially trained health care professional who can offer practical advice on how to manage the challenges you face at home or at work and help you maintain your independence for as long as possible.

For information on adaptive devices, download our fact sheet from www.parkinson.org/library or call the NPF Helpline at 800-4PD-INFO (473-4636).

Sleep

Without a good night's sleep, neither the body nor the mind functions at its best. PD and Parkinson's medications can disturb normal sleep cycles. In addition, as we age, changes in the sleep-wake cycle often occur. This can include waking up earlier than in younger years; waking up more often during the night; having difficulty going back to sleep; and sleeping more during daytime hours.

Sleep-related symptoms are reported by more than 75% of people with PD. While the exact cause of these problems is uncertain, the most common complaints include the following:

- Difficulty falling and staying asleep
- Excessive daytime sleepiness
- Talking or yelling out while asleep
- Vivid dreaming
- Leg movements, jerking, cramping
- Difficulty turning over in bed
- Waking up to go to the bathroom

Here are some general guidelines for maintaining a normal sleep cycle:

- **Maintain a regular schedule;** get up and go to bed at the same time every day.
- **Get plenty of bright light** exposure, particularly natural daytime light.
- **Decrease fluids** for four hours before bedtime. Go to the bathroom just before getting into bed.
- **Reserve the bed only for sleeping and intimacy.** Reading, watching TV, eating, and other activities can confuse the mind about what is expected when you get into bed.
- **Set the thermostat** for a slightly cool bedroom temperature for sleeping.
- **Make a regular, relaxing bedtime routine** a habit.
- **Lie down to sleep only when sleepy.** If you are unable to fall asleep after 15 minutes, get out of bed and engage in a relaxing activity like listening to music, meditating, or reading until you are sleepy.
- **Keep lighting and noise at comfortable levels** when trying to sleep.
- **Sleep as much as needed to feel refreshed,** but avoid spending too much time in bed.

Enemies of restful sleep include the following:

- Alcohol, caffeine and other stimulants, such as nicotine
- Heavy late night meals (although a light snack at bedtime may be helpful)
- Heavy exercise within 6 hours of bedtime
- Thoughts or discussion before bedtime about topics that cause anxiety, anger, or frustration
- Watching the clock

Mental Wellness

Like people with other chronic diseases, people with Parkinson's often struggle with mental health difficulties, but maintaining a positive attitude is one of the healthiest things you can do in response to a diagnosis. While PD is known to impair many aspects of movement, research from the National Parkinson Foundation's Patient Outcomes Project, the largest-ever clinical study of Parkinson's, found that two non-motor symptoms — depression and anxiety — are the biggest factors impacting the overall health status of people with PD.

At first, it can be hard to accept that the disease is not a sentence to decline and disability. However, with appropriate treatment, and working with your care team, you can learn to cope with the illness and sustain the energy, activities, and relationships that give life meaning and joy.

Depression

While not everyone with Parkinson's will be affected, depression is common in PD, with at least 50 percent of those diagnosed with PD experiencing some form of depression during their illness. This is not just a reaction to the diagnosis. The same chemical processes in the brain that lead to movement symptoms also impact mood.

Dopamine, which is depleted in Parkinson's disease, plays a role in mood as well as movement. Other chemicals are affected by PD, including serotonin, which is also involved in mood. While depression can sometimes go away spontaneously, in many cases it can continue for a long period of time, affecting energy levels, productivity, and close relationships.

People with Parkinson's, as well as caregivers, family, and friends, should be on the lookout for these signs and symptoms of depression:

- Feeling sad or blue most of the time
- Frequent, spontaneous crying
- Lack of energy
- Difficulty concentrating
- Loss of interest in things that you usually enjoy
- Feeling hopeless, helpless, or guilty
- Changes in eating and or/sleeping habits
- Early morning waking

If you experience mood changes and low spirits for more than two weeks, consult your health care provider. Depending on your situation, your doctor may prescribe an antidepressant medication, make a referral to a professional counselor, or recommend a combined approach.

Anxiety

Anxiety is also common in PD, with up to 40 percent of people experiencing an anxiety disorder at some point during their illness. Symptoms of mild anxiety include worrying, brooding, or over-preparing too far in advance for events that previously seemed easy to handle. Some people also experience fidgeting and the urgent need to move about as part of their anxiety complex. Counseling can be extremely helpful in learning to cope with anxious feelings. Your doctor can also recommend helpful anti-anxiety medications or relaxation techniques if anxiety is part of your Parkinson's profile.

For resources and information about mood changes in PD, contact the National Parkinson Foundation Helpline at 800-4PD-INFO (473-4636) or helpline@parkinson.org.

A Healthy Spirit

For purposes of this discussion, it is important not to confuse issues of spirituality with issues of religion. Certainly these spheres overlap, but to clarify, we are using the word spirit to symbolize that most basic core of who we are and how we relate to our world. The desire to maintain a healthy spirit can be overshadowed by heroic efforts to maintain good physical and emotional health.

The discovery and nurturing of your spirit is a personal process, requiring time and energy. It may involve learning to appreciate time alone, designing a life that is less hectic, or renewing a love affair with books or photography. Contributing to community service and the joy of giving to others without expecting anything in return can enrich your spirit. Finding ways to enjoy nature's wonders can put us in touch with that essence called spirit. Whatever the path, a healthy outlook is vital to knowing and caring for yourself.

Chapter 4

Taking Charge of your Health Care

Parkinson's disease will require you to take an active role in your health care. Before PD you many have visited your primary care doctor only when you were sick or in need of a physical exam. After diagnosis, you will likely be seeing a neurologist in addition to your primary doctor. With the help of your care providers, you will be making important decisions about the type of treatment that is best for your individual case of Parkinson's. This will require learning about the different treatment strategies, side effects, and possibly even experimental treatments. Your health care team and the National Parkinson Foundation are good resources for helping you take charge of your health and make informed decisions about your care.

Health Care Team

Health care professionals are among the most important resources for a person with Parkinson's. While doctors or nurses are often the first health care providers with whom you will have contact, there are many other health professionals whose expertise can prove invaluable in the course of your PD. If you are fortunate enough to live near a movement disorders practice where there is an interdisciplinary care team, familiarize yourself with their resources for comprehensive care. The following list describes some potential members of your health care team.

- **Neurologists** are doctors who specialize in problems with the nervous system. A **movement disorders specialist** is a neurologist who has completed an extra one or two years of training in movement disorders such as PD. The neurologist will keep track of your disease progression, work with you to prescribe appropriate medications, monitor your response to therapies, and make recommendations for care.
- **Primary care providers (PCPs)** are usually internists or family practice physicians who will manage your overall health and problems outside the Parkinson's arena. Your PCP should receive periodic reports from your neurologist regarding the current management of your PD.
- **Physician's assistants (PAs)** have an advanced degree and work under the supervision of a physician. PAs can work with specialists as well as primary care providers.
- **Nurses** are often your primary contact and the central coordinator of your care. Nurses can provide you with information and connect you to needed resources, and they may facilitate research studies. **Nurse practitioners (NPs)** are registered nurses (RNs) who have an advanced degree and who have passed special licensing requirements. NPs can perform physical exams and prescribe medications and other therapies. They often work with a physician, although they can function independently.

- **Social work professionals** work in variety of hospital and community settings. Many provide individual, couple, and family counseling to help you cope with stressful life events. Social workers often lead support groups. They can also connect you with a variety of community resources and help you and your family plan for the future by helping you sort out and resolve issues associated with insurance, housing, and disability.
- **Physical therapists (PTs)** are licensed professionals who evaluate and treat mobility problems such as flexibility, strength, balance, posture, and walking. They design exercise programs and provide training to meet an individual's needs. A physical therapist can also help family caregivers by teaching safe and effective ways to provide assistance.
- **Occupational therapists (OTs)** help to modify or adapt activities of daily living, which include dressing, feeding oneself, getting in and out of bed, writing, and performing in the workplace. An occupational therapist can address issues of safety and independence in the home. An OT may use compensation strategies, adaptive equipment, and /or exercises to promote fine motor and other skills.
- **Speech-language pathologists (S-LPs)** are healthcare professionals trained to assess, manage, and treat speech, voice, memory, and swallowing problems. Treatment with an S-LP can improve problems you may experience with communication, swallowing, eating, and thinking changes.
- **Pharmacists** provide valuable information about prescription medication, a mainstay of Parkinson's treatment. Pharmacists can provide counsel on possible drug interactions and side effects. Try to use the same pharmacy all the time, so there is a record of all medications you are currently on and have taken in the past.
- **Neuropsychologists** are licensed psychologists with expertise in how behavior and cognitive (thinking) skills are related to brain structure and symptoms.
- **Psychiatrists** are physicians who specialize in the diagnosis and treatment of mental, behavioral, or emotional problems such as depression and anxiety.
- **Psychologists** can work with individuals and family members by providing advice and counseling for coping with the disease.
- **Dieticians/nutritionists** can help you design an eating plan for overall health. A dietician can be particularly helpful if you have trouble chewing or swallowing, difficulty preparing nutritious meals, or problems with your weight.

Tips for Communicating with Your Health Care Team

The following tips can help you communicate your needs effectively and efficiently to get the most out of your appointments with the health care team:

- Keep regular appointments with your doctor to allow him or her to reexamine your motor performance, hear how you have responded to medications, and make necessary changes.
- In between appointments, take notes as issues come up, so you know what you want to discuss. Before the appointment, prioritize the issues, so during the visit you have time to discuss your chief complaint(s) or the area(s) where you most need help or advice. Go to parkinson.org/factsheets and download the **“Medical Appointment” worksheet** to help you organize your thoughts for the visit.
- If possible, take someone with you to your appointments. It helps if this person can share objective input regarding your progress. This person should also take notes during the visit, so you have a record of any changes or instructions you can review or discuss later at home.
- Take your medications with you to your appointments, so the doctor and nurse can easily review them.
- Ask the doctor or nurse to write down any instructions they give you, then review the instructions with them to be sure you understand the instructions clearly and have any questions answered.
- Be totally candid with your doctor about how you are doing and all medications you're taking, including over-the-counter items and herbal supplements. It happens too frequently that in response to the physician's query of, “How are you doing?” the patient will modestly reply, “oh just fine,” while the partner will volunteer, “Doctor, he's not fine at all!”
- To reduce your chance of sitting in the waiting room for a long time, request the first appointment of the day or the first afternoon appointment.
- Most doctors have a nurse or other staff member who returns patient calls between office visits. Many practices return calls at the end of the day to avoid interrupting patient appointments. If you call with a question and are awaiting a return call, keep all the relevant information near the phone: notes of medications, any problems you are experiencing, pharmacy numbers, etc. If possible, take the call yourself rather than communicating through a family member.

Get Organized and Be Prepared

It is a good idea to maintain a personal health file at home, including dates of any major diagnoses, serious illnesses, or surgeries; pertinent test reports and immunizations records; allergies to medication; and a list of current medications, including non-prescription drugs and supplements. You should also include a list of medications that you have taken in the past and the reason that they were discontinued. Keep this file up-to-date.

All adults, whether they have Parkinson's disease or not, should have written advance directives. An advance directive puts your medical care preferences in writing, stating what kind of treatment you want in case you are ever unable to communicate your medical decisions. Advance directive forms vary from state to state. Most doctors, nurses, or social workers can guide you to information about advance directives, or you can obtain information and forms for your state by contacting the U.S. Living Will Registry at www.uslivingwillregistry.com or 800-LIV-WILL (548-9455).

Finding Information on the Internet

The internet can be a great resource for health information. Unfortunately, it can also be a source of false or misleading information, so it is wise to be cautious when using the internet to access information important to your health. There are three key questions to consider when evaluating information online (or in print!):

1. **Who said it?** Who is responsible for the site? Is it the government, a university, or a well-known health related organization? Is it a manufacturer of a drug or another product? And what is the purpose of the site? The site should have a link titled "About" that states the purpose of the site or the organization. Is the purpose to promote or sell a product, or to educate? All of this information should be easy to find.
2. **When did they say it?** Is the information current? Does the information include the date that it was published or updated?
3. **How did they know?** Is the information on the site documented? Are there references for medical facts and figures?

More information to help you evaluate health information can be found at www.trustortrash.org and www.cancer.gov/about-cancer/managing-care/using-trusted-resources.

For information on Parkinson's disease, your first stop should be www.parkinson.org!

Evaluating Research Reports

New drugs and other treatments for PD often garner attention in the popular press, and headlines can send people searching for a new drug. Often, a closer look reveals that the new medication is only in the early stages of research and years away from becoming an available treatment. Taking some time to review the research can help determine the best way to use the new information.

Following are some questions to ask when evaluating clinical studies of new medications and treatments for PD.

- **What is the source of the information?** Where was it published? It may have been published in a reliable medical journal, at a scientific conference, in a magazine, or by another source. Check with a member of your health care team to determine if the source is reputable.
- **How many people participated in the study?** In general, the higher the numbers, the more reliable the results.
- **How was the study designed?** There are several basic study designs, and some are considered better than others.
 - **Placebo-controlled studies** are those that use a study drug and a placebo, which is a pill or other treatment without any medicine in it.
 - **Single-blind, placebo-controlled studies** are those in which the study participant OR the researcher evaluating the participant's response knows if the person is receiving the actual study drug or placebo. The other party does not know, making them "blind."
 - **Double-blind, placebo-controlled studies** are those in which neither the study participant nor the researcher know if the participant is receiving the study drug or placebo. Double-blinded studies are thought to be the most valid study design, though they are not always possible.

Your health care team can be an invaluable resource for helping to interpret research studies.

Clinical Trials

There is a lot we still don't know about people and their health. Different forms of medical research help us learn more. Studies that involve people—human subjects—are called clinical studies. At some point, you may be asked to volunteer for such a study. Clinical trials aim to test new interventions – this could be a drug, surgery, or therapy like exercise or diet guidelines – to make sure they are effective and safe. While participating in a research study may help you get a new treatment before it is available to the public, there are also risks that you should clearly understand.

For more information about clinical trials and to find a study you might be eligible for, visit www.clinicaltrials.gov or call the NPF Helpline at 800-4PD-INFO (473-4636).

Chapter 5

Accepting and Adapting to PD

If you have recently been diagnosed with Parkinson's disease, it is important to recognize that the condition requires adaptation. Learning to pace yourself, prioritize goals, and make timely use of self-care strategies to enhance your well-being can make all the difference in how you enjoy life and maintain your independence. Accepting and adapting to PD will require ongoing adjustments over the course of your lifetime.

For most people, the first concern is what impact PD will have on their ability to walk, talk, eat, sleep and take care of themselves normally. Yet interwoven with the physical effects of the condition are new concerns for one's family, ability to work and social life. The emotional impact of dealing with widespread changes will be influenced by many factors, including your attitude towards living with the disease, the support of people in your life that are important to you and your spiritual and cultural beliefs.

Stages of Adjustment

A natural first response to a PD diagnosis is feeling like you are facing a loss of freedom and independence. You may deny it – “This can't be happening to me” – or question it – “Why is this happening to me?” These feelings are typical of an emotional reaction to loss, and they can even evolve into depression. Eventually, however, the negative feelings are likely to give way to acceptance of the diagnosis and the realization that PD is a condition with which you must learn to live.

Different cultures have unique views of health care and chronic illness, and PD affects people from all cultures and ethnicities. Your background and beliefs will influence how you seek health care and how you adapt and adjust to PD.

It is important to remember that the impact of PD extends beyond the person who receives the diagnosis. Parkinson's also affects your family, friends, and co-workers who care about you. In addition to their concern for you, family members and friends will also be concerned about how PD will impact them.

Following the diagnosis, most people – including people with Parkinson's as well as care partners and family members – will go through several stages of adjustment to Parkinson's. Each person will experience the stages at a different pace and in a different order, and some stages may recur. This is normal.

You may not progress through all the stages of adjustment, and you may not experience them in any particular order. Like other aspects of PD, adjusting to the disease is an individual experience, and as the disease progresses, there will be new adjustments to make. It may be helpful to talk with a professional counselor, spiritual leader, or close friend or family member throughout the process.

- **Denial:** This response may be prolonged if symptoms are mild or the correct diagnosis is not made early in the course of the disease. Symptoms of PD appear gradually and episodically. Ironically, denial can be a useful coping mechanism if it allows one to largely ignore symptoms and go on with life as usual. However, if a person refuses to take medication, or someone goes to extremes seeking numerous professional opinions, it may indicate denial as an unhealthy response.
- **Discouragement:** In this phase, people look for some direct cause for the health problems they are experiencing. You might become preoccupied with the "Why me?" question, while searching for something or somebody to blame for the unwanted circumstances occurring in your life.
- **Role conflict:** This happens when people with PD and their care partners become confused and frustrated with the daily fluctuations in symptoms, and when the need arises to reevaluate who is responsible for what tasks in the family. Changing abilities and assuming new roles within the family can cause emotional upheaval. A family coping with these issues often benefits from meeting with a counselor and dealing openly with these conflicts.
- **Identity change:** In this stage, you realize that the disease has had an impact on your life. You recognize that life has changed; become willing to seek out others with the same condition for education and encouragement; and take on the work of achieving your optimal level of independence.
- **Successful adaptation:** Although not a permanent euphoria, this stage represents a level of satisfaction with one's life as it is. Many people exert a degree of control over their illness by assuming an active role in their health care; for example, working with your doctor to choose what medications to take and in what doses.

Adjusting and adapting to Parkinson's is an ongoing process that will continue over the course of the disease, and there is much more to it than is discussed in this chapter. Begin by learning basic information about PD and what you can do to take care of yourself. A good start is with the information in this manual. Support groups and online discussion forums (visit www.parkinson.org/forums) can also be a good source of information. The National Parkinson Foundation's educational book series offers comprehensive information on a variety of topics that may be of interest to you as you seek more and more detailed information about PD. These publications are available free of charge and can be ordered by visiting www.parkinson.org/books or by calling the NPF Helpline at 800-4PD-INFO (473-4636).

Spouse and Partner Adjustments

Having PD raises many concerns for the spouse or partner of a person living with the condition. Partners too can suffer from anxiety and depression over the unknown future and the risk of disability, job and economic loss, and increased dependence. How PD will impact your relationship with your partner will depend greatly on the kind of relationship you had before diagnosis. Strong relationships tend to become even stronger. If you are able to communicate openly and share your feelings and concerns with each other in an accepting manner, chances are you can grow even closer. On the other hand, if either one of you has not been able to communicate openly and honestly about your most intimate concerns, it would be wise to seek out someone who can help you work on your relationship concerns, such as a professional counselor or spiritual leaders. It is possible that the resiliency of adaptation can turn adversity into strength.

It is important that both you and your partner understand the disease. Learn the basics of PD. Include your partner in doctor visits, so you both can have an opportunity to ask questions (and you have two people listening to the doctor's recommendations to make sure you understand everything!). Discuss how PD is impacting your life together and what each of you can do to make things easier. Whenever possible, continue to do the things that you have always enjoyed sharing together. Both partners will need to be willing to make modifications and compromise as your situation changes.

Sexuality

Sexual concerns rank among the most difficult communication issues for many couples. Our perceptions of masculinity and femininity and what we expect from an intimate relationship are as unique as our personalities. Few of us escape from childhood and adolescence with a flawless self-image as the ideal sexual partner!

There is considerable literature offering advice on how to enhance your sex life in general, so this section will focus on the specific effects of Parkinson's on sexual participation and satisfaction. PD affects the autonomic nervous system, and therefore can impact sexual performance. A movement disorder, by its very definition, is going to impact the routine moves involved in a sexual encounter. Decreased agility and flexibility can be a problem. Antiparkinson drugs, as well as many other medications, can negatively impact sexual performance. Depression, which is common in persons with PD, can decrease sexual desire and energy.

Some men with PD (certainly not everyone) experience problems with impotence. The release and widespread use of treatments for erectile dysfunction has proved helpful in many cases. While these medications are contraindicated in certain heart conditions, they are generally safe to use in combination with antiparkinson medication. Consultation with a urologist is recommended to choose the best medical approach when impotence is the chief sexual complaint.

In women, Parkinson's disease may impact libido (the desire to have sex) more than performance. Fertility is probably not affected by PD; young women have successfully carried pregnancies to term and delivered healthy babies. The onset of PD during the perimenopausal years of hormone fluctuations can be particularly challenging. It is important to work with your gynecologist and neurologist to best combine hormone replacement therapy and antiparkinson medications.

In regard to sexual activity, it is important to remind yourself that spontaneity isn't everything! Many of us equate sex with romance; we want it to "just happen." But anyone who's raised young children knows that planning/scheduling time for privacy and intimacy is often the only way it can happen. Many older couples have learned to reserve morning time for sex, because testosterone levels are highest then, making it easier for the male to maintain an erection.

Likewise, Parkinson's motor fluctuations can dictate planning. Arrange for sexual togetherness when your medications are likely to be at peak effect and symptoms are least intrusive. Don't be embarrassed to set the stage. Try silk sheets to reduce friction against bedclothes. Experiment with a new position. Snuggle together in bed, whether or not you have intercourse, to maintain intimacy of skin contact. If sexual problems are not resolving after a reasonable period of time, discuss the situation candidly with your physician.

For a discussion of Parkinson's disease in the workplace, family matters, or involving the children, refer to the next chapter, "Special Concerns of Persons with Young Onset Parkinson's Disease" and to the NPF website at www.parkinson.org/understanding-parkinsons/newly-diagnosed.

Support Groups

Support groups offer educational, social contact, and understanding, as well as opportunities for sharing insights and ways of living with PD. Some people worry that attending a support group and seeing someone with advanced symptoms might be discouraging to the recently diagnosed. More often than not, the experience turns out to be encouraging. There is a good chance that you'll meet people who are doing well despite having had PD for a number of years, responding successfully to drug therapies, and thoroughly enjoying life. In many areas, there are specific support groups for people who have been recently diagnosed, people with young-onset PD, and care partners.

For more information and to find support groups in your area, contact the NPF Helpline at 800-4PD-INFO (473-4636) or visit www.parkinson.org/search.

The Importance of Optimism

Ultimately, your willingness and ability to adapt and implement changes will sustain the energy, activities, and relationships that give your life meaning and joy. A positive approach can help extend your optimal health status for as long as possible. Think of all you have for which you can be grateful. Whatever you can appreciate about your life right now will influence your ability to adjust to living with PD.

Chapter 6

Special Concerns of Persons with Young-Onset Parkinson's Disease

Stan is 44 years old and lives in Madison, Wisconsin, with his wife Ellen and their three children, two dogs, two cars, and a mortgage. His high-pressure job as an industrial engineer pays \$68,000 per year. Until two years ago, Stan's biggest worries were paying the bills, helping move his mom into a retirement center, and the chaos of raising teenagers.

Then Ellen began questioning the occasional tremors in his left hand. Stan's left foot seemed to drag slightly, particularly when he was tired, and his boss complained that his handwriting had become too small to read. At Ellen's insistence, he made an appointment with his family doctor, who said, "Although there's probably nothing to worry about, you should see a neurologist just in case."

The neurologist said Stan was "awful young to have Parkinson's disease" but ran a battery of tests to rule out other maladies and finally determined that Stan should see a movement disorders specialist in Milwaukee.

The movement disorders specialist said Stan did indeed have Parkinson's and would benefit from starting on a low-dose medication to control symptoms. The specialist said, "It's not fatal, though there is no cure. We can treat your symptoms, so don't worry."

"What now?" Stan agonized during the long trip home.

- Will I be able to keep working – should I tell my boss?
- How will Ellen cope with this?
- What should we tell the kids?
- Is it safe for me to drive?
- Could I become an invalid?
- Can I even deal with this?

The questions kept coming...

Young-Onset PD Diagnosis

Most people do not think of Parkinson's as a disease of the young, but it is estimated that five percent of all persons with Parkinson's are diagnosed before age 40, and 15 percent are diagnosed before age 50. The complicated issues of how best to share the diagnosis, when to start medications, and concerns about financial security and job performance all have different implications when one is young.

Clinical features of persons with young-onset Parkinson's disease, or YOPD, may vary from those of their older counterparts. Thirty to 50% of young onset cases begin with **dystonia**, an uncomfortable stiffening or "drawing up" of a muscle group. Dystonias of the foot and calf are common in younger persons with PD. Tremor appears to be slightly less common in younger people, though it is still one of the most troublesome symptoms. Tremor can interfere with routine activities such as shaving, dressing, writing, and many other tasks that require fine motor coordination. Many young people with Parkinson's who are still active in the workplace and community affairs also report that tremors are an embarrassing visible reminder of their disease.

Younger persons with PD are thought to develop earlier motor fluctuations and dyskinesias (involuntary writhing movements) in response to levodopa, the medication most effective in treating Parkinson's. However, overall tolerance to antiparkinson medication and general prognosis (the likely course of the disease) appear to be better than in older people. In part, this may be due to other chronic health problems in the elderly, such as arthritis and heart disease, which can further compromise mobility.

Young-Onset PD Prognosis

Inherent differences in the physical condition of middle-aged vs. older adults do not seem to completely account for the difference in disease progression between the two groups. One measure of disease progression is disability, which refers to an individual's limitations in performing activities of daily living. In one study, older persons with PD had about 80% greater disability compared to younger persons when assessed during their fifth year of levodopa therapy.

Older people with Parkinson's also appear to have significantly more difficulty with cognition. Cognition refers to an individual's mental status. This includes the ability to reason, remember, and exercise good judgment. However, this is a difficult comparison to make, since aging alone is the number one risk factor for cognitive decline.

Parkinson's Disease in the Workplace

It is estimated that 25-30% of people diagnosed with PD are still active in the workforce. Some continue full or part-time employment for many years. While the Parkinson's diagnosis does not necessarily call for early retirement, it does call into question how you can best do your job and minimize work-related stress.

Try to approach your job from a new perspective. Make an outline of your overall responsibilities, then break each area down into individual tasks.

Next, consider whether or not your symptoms will interfere with your ability to carry out each task. Look for alternate ways of doing things. Try to create a schedule that enables you to address difficult or challenging assignments during your peak performance periods, and set aside specific hours for time-consuming efforts like writing reports.

It is natural to be apprehensive about their reactions to the news, but in most cases, it is wise to be candid with your boss and close co-workers about your condition. If your symptoms are noticeable at a particular time, offer an explanation. Honest communication opens the door for the work team to make necessary adjustments to meet your needs without imposing on colleagues.

If you believe your company is one that might discriminate against someone with a disability, you are not legally required to mention your diagnosis to your employer as long as you can adequately perform your work. Legally, making the necessary environmental and workload changes to accommodate special needs is part of the responsibility of your employer. This is an individual decision and often a matter of finding the best time to share your situation.

The Americans with Disabilities Act (ADA) entitles all qualified persons the right to a job, regardless of disability, and requires reasonable accommodations in the workplace for persons with disabilities. Reasonable accommodations include making existing facilities used by employees readily accessible to and usable by individuals with disabilities; job restructuring; part-time or modified work schedules; reassignment to vacant positions; acquisition or modifications to equipment or devices; and other similar adaptations. Most reasonable accommodations can be made at minimal cost to employers.

In terms of seeking a *new* job after you're diagnosed with PD, the ADA dictates that employers may not inquire about disability until after reviewing all job qualifications and making a conditional job offer. Even then, you are required to answer questions about your disability only if it might affect performance of specific job functions.

For more information on your rights under the Americans with Disabilities Act (ADA), visit www.ada.gov or www.dol.gov/odep.

Family Matters

Many younger people with Parkinson's have young families, and the diagnosis affects all members of the household. The well spouse may already be wearing multiple hats as co-breadwinner and parent, and now must add care partner to his or her identity! The spouse/partner may have their own health problems to worry about in addition to the concerns of the person with PD. It is a complicated situation that requires patience, stamina, and creativity from everyone involved.

Another dynamic unique to YOPD is that older parents are often shocked to learn that a middle-aged child is diagnosed with a condition usually associated with the elderly. Their apprehension can build if you are someone on whom they're dependent for emotional or even financial support.

Marriage is the relationship most often studied and referenced in the literature on caregiving. The care partner of a young or middle-aged person with PD faces particular challenges. The frustration of dealing with incorrect or delayed diagnosis can take its toll. Some couples are relieved to finally get the diagnosis of PD, because it is less terrifying than the alternatives they've imagined or just not knowing.

It is important for couples to keep an open dialogue about the feelings and experiences of living within the new parameters imposed by Parkinson's. Eventually the healthier spouse may need to assume some of the tasks and roles in the family previously managed by the individual with PD. This is an ongoing negotiation. Even if you continue to manage all your previous responsibilities, you may be slower performing these tasks. Your partner may wonder when to simply observe and when to help.

Spouses and significant others in the family often express frustration at not knowing how to interpret "on" and "off" periods of motor function. As one wife shared with her husband's doctor, "It's hard to tell when he really can't do something, and when he's using the PD to hand off the unpleasant task to me!"

Couples who manage best in the face of chronic illness begin talking together from day one about how the disease is affecting daily operations in the family and what each can do to make things easier. Care partners who manage best in the long run are those who learn early to be flexible, state their own changing needs clearly, and protect regular blocks of private time to meet those needs over the years. This is not selfish. It is crucial to the well-being of the person with PD and the family that the care partner maintain his or her own physical and mental health.

Caregivers play a dual role: caring for someone with Parkinson's, and taking care of yourself. NPF's ***Caring and Coping*** workbook is a comprehensive guide for caregivers that contains tips and tools to make the caring journey as productive as possible with the least amount of stress. To order your free copy, visit www.parkinson.org/books or call the NPF Helpline at 800-4PD-INFO (473-4636).

Some partners – and people with Parkinson's – gain strength from becoming active in the greater Parkinson's community. Many of the most powerful advocates for better services and more research dollars for PD are those with the disease and their devoted family members.

When you are ready to get involved in the Parkinson's community, visit www.parkinson.org/get-involved. There you will learn how to raise awareness and funds to help the 1 million people with Parkinson's in the U.S. get better care and live better lives today.

Involving the Children

Younger families must deal with the unique issues of communicating the diagnosis and sharing the daily ups and downs of PD with young children and teenagers still living at home. It is important to consider how PD might affect your children and what can be done to continue living a full family life with PD.

Children will absorb the reality of Parkinson's disease in the family "by osmosis" as well as assimilating what they are told directly. They know instinctively when something is not quite right in the family, whether it's physical or relational. For example, they can likely sense your frustration with tremors or difficulty walking and are capable of both empathy and sympathetic offers of help. Whatever their ages, attempting to hide the diagnosis from children is usually a mistake. Vital energy used to keep the secret is better channeled into coping with the demands of maintaining a marriage, making a living, and raising a family.

Kids need reassurance that their mommy or daddy is going to be OK, even though there are problems that show up some days more than others. They need reassurance that you will “be there” for them, just like always. They might imagine something much worse than the truth, so you can explain that PD is not like the lung cancer a grandpa died from, and it is not contagious like chicken pox. Matter-of-fact answers to specific questions can help children cope with having a parent who may have special needs.

Download our fact sheet **“Parkinson's and Your Children/Teenagers”** at www.parkinson.org/library for tips and tools on sharing the diagnosis, maintaining privacy, and supporting your kids in their understanding and acceptance of the disease. You can also download a fact sheet to give to your kids to help them cope: **“My Parent Has Parkinson's. What Does It Mean?”**

Teenagers

What about teenagers – those young adults who may be grossly embarrassed even by parents who *don't* have Parkinson's disease?!

Sometimes adolescents can benefit from professional counseling to help ease the struggle of having a parent who is less than physically perfect. Still, it is important to retain key roles as the authority, model, and mentor, rather than attempting to be a pal with or confide in your young adult son or daughter.

Older teens may need assurance that they will still be able to go to college or that you do not expect them to be surrogate caregivers. On the other hand, a mature teenager can get great satisfaction from pitching in with chores or chauffeuring tasks that may once have been the sole domain of the parent with PD.

A Word about Stan

Wondering about our friend introduced earlier? He still has the wife, three kids, two dogs, three cars now, and a (lower interest rate) mortgage. Two years after diagnosis, he retains his job in engineering, and he received clearance last month to telecommute from home two days per week.

Ellen's gone back to school to finish her degree and obtain a teaching certificate. Their oldest daughter Sherry just got her driver's license, which is nerve-racking, but also adds another family member available for taxi and errand duty.

Stan's neurologist recently increased the dosage of his dopamine agonist. They've discussed adding Sinemet to his regime, but Stan feels like he's doing pretty well for now. His golf game has suffered a little, but not so much that he's embarrassed to play. He feels better overall when he makes time to go to the gym twice a week.

In short, he's dealing with it – and living well.

Glossary

Acetylcholine: A chemical messenger in the brain (see neurotransmitter) that is involved in many brain functions, such as memory and control of movement; it is released by cholinergic nerves.

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

Atypical parkinsonism: A group of brain disorders that initially look like Parkinson's disease, but differ in the course of the disease and response to antiparkinson medications. The term is used interchangeably with Parkinson's-plus syndromes.

Bradykinesia: The slowness of movement seen in people with Parkinson's disease; one of the four main motor symptoms of PD.

Cholinergic system: The system of nerve cells that use the neurotransmitter acetylcholine to send messages.

Deep brain stimulation (DBS): A type of surgery used to treat the motor symptoms of PD.

Dopamine: A chemical messenger in the brain (see neurotransmitter) that regulates movement and emotions.

Dopaminergic medication: Medications that increase the level of dopamine in the brain and are typically used to treat Parkinson's disease (i.e., carbidopa/levodopa and dopamine agonists).

Dysarthria: A group of speech disorders caused by disturbances in the strength or coordination of the muscles that produce speech as a result of damage to the brain or nerves.

Dystonia: Involuntary muscle contractions that cause slow, repetitive movements or abnormal postures.

Festination: Short, shuffling steps.

Freezing: Temporary, involuntary inability to move.

Hypomimia: Decreased facial expression due to rigidity of facial muscles.

Idiopathic: A term used to describe a disease with no known cause.

Levodopa: The medication most commonly given to control the motor symptoms of Parkinson's; it is converted in the brain into dopamine

Micrographia: Change in handwriting, with script becoming very small.

Motor fluctuations: Sudden, unpredictable changes in ability to move. Also called "on-off" fluctuations.

Motor symptoms: Parkinson's symptoms that affect movement, including tremor, rigidity, bradykinesia and postural instability.

Movement disorder: A neurological condition that affects your ability to move.

Movement disorders specialist: A neurologist who has completed one to two years of additional training in treating movement disorders such as Parkinson's disease.

Neurodegenerative disorder: A disease characterized by the loss of cells of the brain or spinal cord, which over time leads to dysfunction and disability; Parkinson's disease, Alzheimer's disease, and amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease) are all examples.

Neurogenic orthostatic hypotension (nOH): Orthostatic hypotension (OH) is a drop in blood pressure that happens within a few minutes of standing up. Parkinson's disease and some other diseases can cause OH – in this cause, it is called neurogenic OH, since it is related to dysfunction of the nervous system.

Neurological disorder: A disorder of the brain or other parts of the nervous system (spinal cord, other nerves).

Neuroplasticity: The brain's ability to reorganize itself by forming new connections. This allows the brain to compensate for injury and disease and to respond to new situations and changes in the environment.

Neuron: A specialized cell that transmits nerve impulses from one part of the body to another.

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

Non-motor symptoms: Symptoms associated with PD that are not related to changes of the motor system. These include pain, fatigue, anxiety, depression, drooling, sweating, urinary changes, heart palpitations, dizziness, and more.

On-off fluctuations: See "motor fluctuations."

Parkinson's-plus syndromes: Term used interchangeably with atypical Parkinsonism.

Parkinsonism: Broad term used to describe Parkinson's-like symptoms (resting tremor, slowness, poor balance, walking problems, etc.).

Postural instability: Difficulty with balance; unstable balance.

Progressive: A term used to describe a disease or condition that worsens over time.

Retropulsion: The tendency to fall backwards.

Rigidity: Stiffness in a limb or joint.

Substantia nigra: A region in the brain where cells produce dopamine.

Tremor: Involuntary shaking of a body part.

About the National Parkinson Foundation

At the National Parkinson Foundation (NPF), we make life better for people with Parkinson's through expert care and research. Everything we do helps people with Parkinson's actively enjoy life. We continue to bring help and hope to the estimated one million individuals in the United States, and four to six million worldwide, who are living with Parkinson's disease. A wealth of information about Parkinson's and about NPF's activities and resources is available on our website, www.parkinson.org.

Here are some of the highlights of our organization:

- NPF has funded more than \$189 million in research and support services to improve the lives of people with Parkinson's. We continue to be a major funder of research programs. NPF's *Parkinson's Outcomes Project*, the largest-ever clinical study of Parkinson's disease, includes nearly 10,000 patients from four countries and is designed to change the course of the disease.
- NPF Centers of Excellence – chosen from the top ranks of academic medical centers where dedication to exemplar patient care is paired with groundbreaking research – comprise the first international network to focus on how to improve care for people with Parkinson's. The network includes 41 Centers of Excellence that deliver care to more than 50,000 Parkinson's patients. We drive and set the standard of expert care in Parkinson's through this network. To find out if there's a Center of Excellence near you, go to www.parkinson.org/search.
- The *Aware in Care* kit is part of our commitment to helping people with Parkinson's live well today and in the future. The life-saving kit provides people with PD and caregivers the tools they need to get the best and safest care in the hospital. Order your free kit at www.parkinson.org/aic.
- NPF helps people with Parkinson's every day by providing support, education, and free resources through our toll-free Helpline: 800-4PD-INFO (473-4636) or helpline@parkinson.org. Our PD information specialists are from various allied health professions and are here to support you in any possible way.
- This book is part of NPF's educational book series, which addresses important topics for people with Parkinson's. All our publications are available free of charge and can be ordered online at www.parkinson.org/books or by calling the NPF Helpline.
- *Moving Day*[®], A Walk for Parkinson's, brings local communities together to raise funds and awareness about the disease that impacts you, your family, and friends. Visit www.npfmovingday.org to find an event near you!

The National Parkinson Foundation is proud to provide educational materials at no cost to individuals 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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