DAVIS PHINNEY
Foundation for Parkinson's
Inform. Connect. Inspire.

EVERY VICTORY COUNTS®

New Content Collection

Excerpts from the 7th Edition

BY THE DAVIS PHINNEY FOUNDATION
With contributions from Parkinson's experts, including healthcare providers, researchers, people with Parkinson's, and care partners

With artwork and photos throughout created by members of our Parkinson's community

Welcome to our Collection of New Content from the 7th Edition of our *Every Victory Counts*® Manual

If you already own a previous edition of *Every Victory Counts*, this downloadable collection is for you. This PDF will provide you with access to some of the most significant additions from the 7th Edition without needing to get a whole new book.

The New Content Collection includes...

- New introductions and section openers written by Davis Phinney
- Two fully revised introductory chapters, offering a refreshed foundation for understanding Parkinson's and taking action after diagnosis
- A new final chapter, highlighting the vital role of community and connection.
- New essays on topics such as holistic care, advanced therapies, apathy, sexual intimacy, social isolation, clinical trials, living alone with Parkinson's, and more.

We hope these pages offer practical insights, encouragement, and new ideas to support you. You may also wish to visit **dpf.org/evc-resources** where you can download our updated Medication Guide, new printable worksheets, and explore some of the supplemental resources we recommend throughout the book.

TABLE OF CONTENTS

In the new edition of the *Every Victory Counts* manual, Davis acts as a guide throughout the book. The following include his introduction to the book along with all the section introductions he wrote to help provide his perspective along the way.

EVERY VICTORY COUNTS: A MESSAGE FROM DAVIS PHINNEY

Photo by Kevin Scott Bachelor, courtesy of Trek

When I was diagnosed with Parkinson's 25 years ago at age 40, I felt as though my world had been turned upside down. As a former professional cyclist, I had always thrived on challenges, pushing my limits and striving for excellence. Yet, Parkinson's presented a different kind of challenge—one that threatened not only my physical abilities but also my cognitive function. Indeed, my generally positive outlook on life felt trapped under the weight of my diagnosis. But it didn't have to be this way, and with the *Every Victory Counts* manual, we invite you to discover that living well with Parkinson's is not just possible, it's within reach.

This manual is a trusted guide for anyone facing the realities of Parkinson's, filled with practical advice, personal anecdotes, and the wisdom of those who are on this road alongside you. I firmly believe that every small victory—whether it's getting out of bed, taking a walk, or enjoying a sunset—deserves recognition. These victories, no matter how minor they may seem, accumulate to create a life filled with purpose, and, often, joy.

Over the years, through the work of the Davis Phinney Foundation and the countless people who have shared their stories with us, I've come to see that living well with Parkinson's is about more than information or strategies. A friend of the Foundation recently wrote about the power of resilience, resistance, and accompaniment, and those words ring true for me. Living well requires resilience: the ability to bounce back and stay rooted when life turns upside down. It requires resistance: the determination to push back against the despair, stigma, and isolation this condition can bring. And it requires accompaniment—or as my Spanish-speaking friends say, *acompañamiento*: the experience of not walking this path alone, but together.

The *Every Victory Counts* manual emphasizes the importance of community, optimism, and proactivity. It shares strategies that have worked for me and others, from exercise

and nutrition to mental health and emotional support. My hope is that you will find inspiration in these pages, empowering you to take control of your health and embrace each day with intention.

Let this book be a helpful companion on your Parkinson's path. Together, we can redefine what it means to live well with Parkinson's. Remember, it's not just about surviving; it's about being fully alive—with purpose, connection, and joy—one victory at a time!

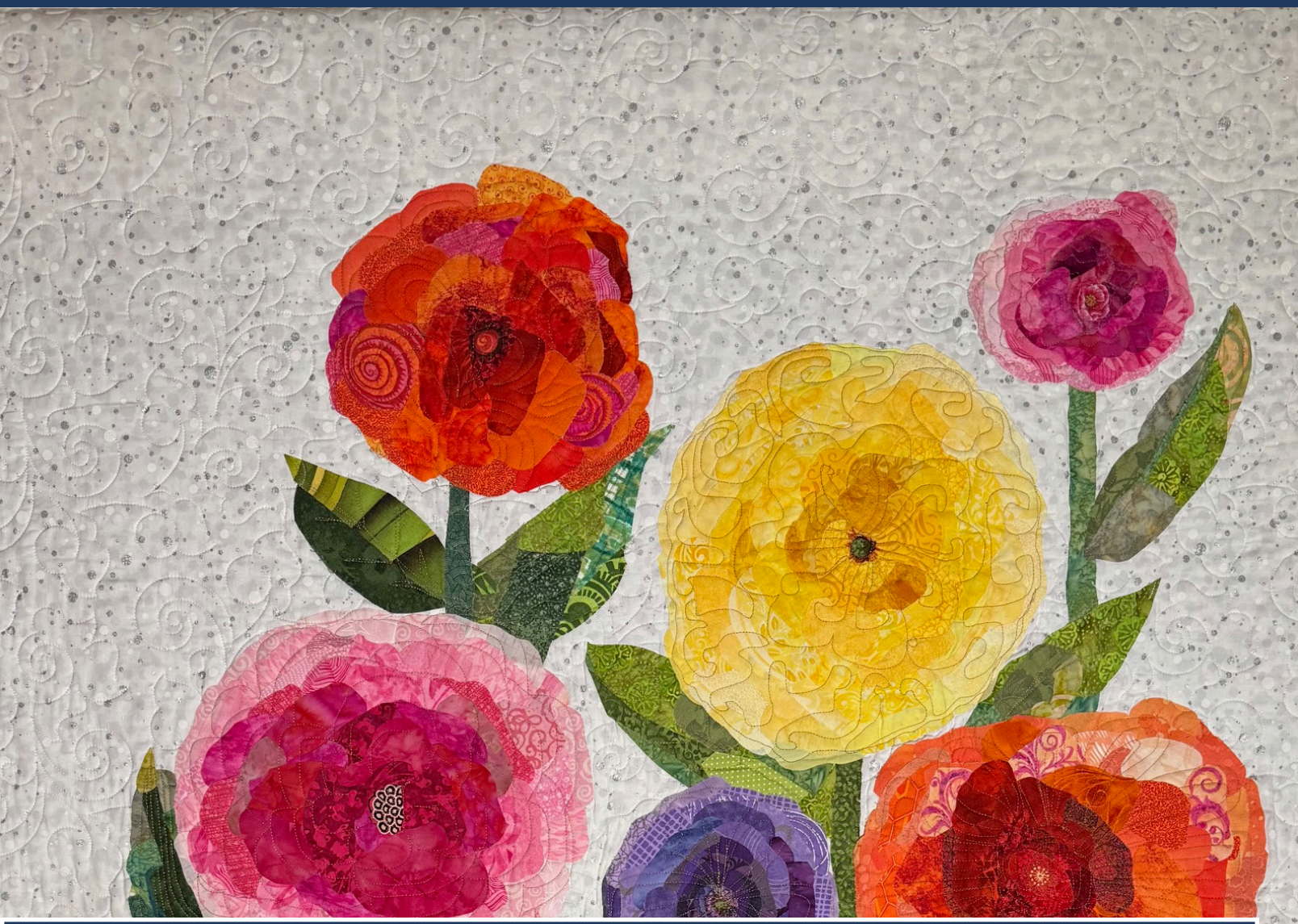
Davis Phinney is an Olympic bronze medalist and Tour de France stage winner who has celebrated the most victories of any cyclist in American history. From the late 1970s until his retirement from professional cycling in 1993, Davis achieved more wins—328 victories in all—than any other US cyclist. In 2000, after years of feeling not quite right, and an almost endless round of tests, Davis was diagnosed with young onset Parkinson's (YOPD). Realizing early on that he could take action to feel healthy and strong despite his Parkinson's, Davis started the Davis Phinney Foundation for Parkinson's, which has become a leading source for education and resources to help people with Parkinson's take action to live well today. Davis lives in Boulder, Colorado, with his wife and fellow Olympian, Connie Carpenter Phinney. They have two grown children, Taylor and Kelsey, who are involved with the organization in a variety of ways. Davis continues to celebrate the daily victories in his life, inspire others by living well, and share his message of optimism with those who need it most.

Introducing Parkinson's

When I was diagnosed with Parkinson's at age 40, my world shifted in ways I couldn't have imagined. At the time, there wasn't much information, and my wife Connie and I often felt like we were piecing things together on our own. That's one of the reasons we created the *Every Victory Counts* manual. It's the guide I wish I'd had then, and I hope it helps you navigate your life with Parkinson's with a little more clarity and a lot less fear.

If you've just been diagnosed, you probably have a thousand questions. I know I did. And the truth is, even after 25 years of living with Parkinson's, I'm still learning. These first chapters give you an overview—not everything you'll ever need to know, but enough to help you begin. Remember, you don't have to do it all today. Living well is about resilience, patience, and connection. And we're in this together.

— DAVIS PHINNEY



Your Prescription for Living Well with Parkinson's

One note about the chapters ahead: they don't start with medications. That comes later. First, we write about what you can do to take care of your mental health and nourish your brain and body, through exercise, good nutrition, and tending to your emotional health.

Medications matter, but what is true for all of us is that moving our bodies, connecting to others, and caring for ourselves makes a difference from day one.

I've learned that victories are in the choices we make right from the outset: to exercise even when it's difficult; to share our struggles instead of carrying them alone; to eat well; to rest; and to focus on, and amplify, what we can do. These choices build us up over time, giving us hope, and creating a sustainable path towards living well.

— DAVIS PHINNEY

Understanding Parkinson's Symptoms

Before I was first diagnosed, the symptom that bothered me most was foot cramping. Then, tremor showed up. Parkinson's has a way of continuously challenging us and one of the difficult aspects is not knowing what might come next.

This section takes us through the most common motor and non-motor symptoms. It is meant to be a resource you can return to, a way to prepare you for surprises.

But don't assume every symptom in these pages will show up for you. While there are certain similarities, Parkinson's is subtly (and not so subtly) different for each of us. Understanding the symptoms is important, but living in fear of them steals today's victories. Knowledge is imperative, yes, but so is presence—and the concept of mindfulness, which is basically keeping our focus on right now, is vital to living well.

— DAVIS PHINNEY

Parkinson's Care, Treatments, and Therapies

When it comes to managing your Parkinson's, there are more choices today than ever before. Around the world, research is ongoing to find new ways to treat Parkinson's.

These chapters introduce the types of providers you might see — from neurologists to speech therapists—along with therapies they recommend. This includes not just medications but rehabilitation therapies and next-step treatments. But keep in mind, there is no single best way to manage everyone with Parkinson's.

Living well with Parkinson's is not about following one perfect plan. It's about building a team, exploring your options, and maintaining an open dialogue with your care team about what methods and medicines work best for you.

— DAVIS PHINNEY

The Parkinson's Community

If there's a silver lining to Parkinson's, it's the people. The community. Our community. Over the years, I've found that connection is as essential to living well as any treatment. That's why we close this *Every Victory Counts* manual with stories reflecting the power of our community and the many ways you can be part of it.

In this chapter, my wife, Connie Carpenter Phinney—co-founder of the Davis Phinney Foundation—shares her perspective as a care partner. I know it hasn't been easy for her, and for her efforts on my behalf, I am eternally grateful. Through her mentoring, she also has found both friendship and inspiration. An unexpected gift.

Whether you find our people in a support group, an exercise class, a choir, or simply over coffee, know this: you don't have to live with Parkinson's alone. Nor should you. Community gives us connection, and that, in turn, gives us joy. And together, we discover what it truly means to live well, one victory at a time.

— DAVIS PHINNEY

CHAPTER 1 // PARKINSON'S 101

OVERVIEW

Hearing the words "you have Parkinson's" is life changing.

For some, a Parkinson's diagnosis marks the end of a long and frustrating search to explain a collection of symptoms that didn't seem related. For others, it comes as a sudden shock, resulting in disbelief and even despair. Maybe neither of those descriptions precisely describes your experience, but we know your diagnosis had a deep impact on you.

The good news is that you can live well with Parkinson's, and there are many things you can do to optimize your quality of life. For example, research shows that the experience of living with Parkinson's can be improved by choosing to exercise, manage stress, and eat well. Many new treatments have been identified since we first published the *Every Victory Counts* manual in 2010, and still more are in advanced stages of research.

Whether you were recently diagnosed or have been living with Parkinson's for many years, it's natural to have questions about Parkinson's. In Chapter 1, we'll discuss:

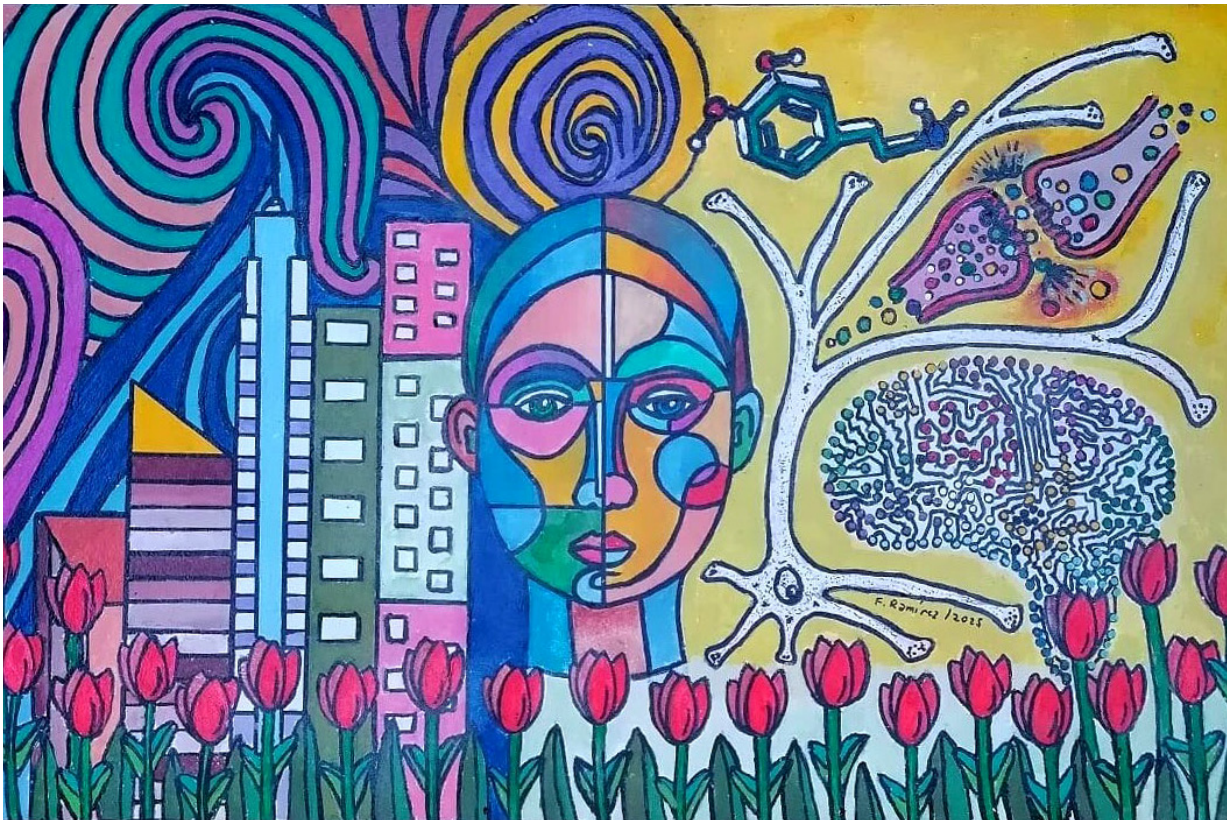
- What Parkinson's is
- What causes Parkinson's
- How Parkinson's is diagnosed—and which tests might help clarify a diagnosis

You'll also find essays from contributors about the road from diagnosis to acceptance and about seeing not just the challenges ahead, but the many possibilities for a joy-filled life.

WHAT IS PARKINSON'S?

Parkinson's is primarily a brain disorder. It is named after an English doctor, James Parkinson, who first described it in 1817. The clearest and most prominent signs of the disorder stem from damage to dopamine nerve cells (neurons) deep inside the brain. This damage causes a decrease in dopamine.

Dopamine is a neurotransmitter: a chemical substance that helps neurons deliver messages to one another. Neurotransmitters coordinate messages about many different systems in the body, and dopamine helps drive motivation, learning, focus, mood, alertness, and movement. Less dopamine in the brain means less control over movement and less mobility, which are two hallmark effects of Parkinson's.



Don't Let Parkinson's Win the Race by Fredy Ramirez

The breakdown and death of dopamine neurons, as well as some other types of brain cells, leads to many of the motor and non-motor symptoms of Parkinson's. Parkinson's is a "neurodegenerative" disease, meaning it causes the brain to change over time. It is chronic and progressive, which means symptoms will change and worsen as time passes. The rate of progression varies from person to person. No two people living with Parkinson's will experience its symptoms or progression in the exact same way.

Because Parkinson's involves damage to the areas of the brain that affect the speed, quality, fluency, and ease of movement, Parkinson's is classified as a movement disorder. Motor symptoms or movement-related symptoms (see Chapter 7) are the most visible elements, but non-motor symptoms (see Chapters 8–10) can have an even more significant impact on your quality of life.

Researchers are investigating whether there are distinct and classifiable "types" of Parkinson's. This is a rapidly changing and important discussion in the field. Understanding well-defined types of Parkinson's could help to clarify diagnosis, improve the accuracy of prognosis, or even identify the best treatments for every individual. Today, the types of Parkinson's that are best understood are those that involve genetic factors.

WHAT CAUSES PARKINSON'S?

BACKGROUND

Today, no one has a comprehensive explanation for what causes Parkinson's. Scientists believe Parkinson's develops from a mix of genetics, environment, lifestyle, and other factors unique to each person.

The complexity of the brain makes it challenging for researchers to determine what actually causes the changes in the brain leading to Parkinson's, but there is a telltale indicator in most people: the formation of clumps (sometimes called "aggregations") of a misfolded protein called alpha-synuclein. These abnormal clumps are called Lewy bodies, and they result in changes in brain tissue that can be seen with a microscope.

GENETIC FACTORS

Researchers know that genes play a role in Parkinson's for some people.

Genes carry the instructions for biological traits like eye and hair color that you inherit from your parents. They control how our bodies produce and shape proteins, and every gene can have slight variations in structure. Most variations are considered "normal" and cause no change in the body or simply account for differences in physical traits. However, some variants can cause the body to create misshaped proteins. These misshaped proteins can cause health problems. Two well-regarded research articles from 2024—one in the *New England Journal of Medicine* and one in *Brain*—say genetic variants are significant factor in the development of Parkinson's for between 13 and 20 percent of people with Parkinson's.[1, 2]

> **My mom and sister both have Parkinson's—we carry the LRRK2 gene—so when I was diagnosed, I knew what it meant. I'm not a doctor, but from my family's experience and my own reading, I understood this was a progressive disease that doesn't get better. I didn't know what the future would hold, only that life wouldn't return to 'normal.' But not being 'normal' is a gift. The Mack truck has already hit us, and Parkinson's has pushed me and my family to make many changes for the better."**
>
> — JILL ATER

The likelihood of a single-gene cause is higher for people diagnosed with Parkinson's before age 50, which is known as young onset Parkinson's (YOPD). However, not every individual that carries the genetic variant develops the condition. A genetic variant is like a seed, but it requires the right "soil"—a specific combination of other genetic, environmental, and lifestyle factors—for Parkinson's to appear. (There's more about young onset Parkinson's, also called early onset Parkinson's, in Chapter 2.)

ENVIRONMENTAL FACTORS

Research over the past two decades strongly suggests that certain toxins increase the risk of developing Parkinson's. For instance, scientists point to an increased risk for people living in rural communities or who drink private well water. This may be due to ingestion of or exposure to certain pesticides that are proven to be toxic to dopamine neurons. Other chemicals, such as solvents used in the dry-cleaning industry, have been associated with Parkinson's as well.

A landmark 2005 review explored the link between Parkinson's and the environment. Several years later, a provocative study from the University of California, Los Angeles, connected Parkinson's to occupational pesticide exposure, as well as living or going to school near pesticide-treated fields.[3,4] A later review of 104 studies found that exposure to certain pesticides and solvents can raise the risk of developing Parkinson's by 33 to 80 percent.[5]

Many of the world's leading Parkinson's specialists are convinced. In 2024, Dr. Ray Dorsey and Dr. Bastiaan Bloem wrote in the *Journal of Parkinson's Disease*, "The main causes [of Parkinson's] are environmental toxicants. Chief among these are certain pesticides, industrial solvents like trichloroethylene (TCE), and air pollution. These are not the only toxicants [tied to Parkinson's], and more may be found."[6]

LIFESTYLE FACTORS

A study published in 2015 identified lifestyle factors that may increase—or decrease—a person's risk of developing Parkinson's. It linked higher risk to drinking alcohol or well water as well as to exposure to anesthesia, manganese, solvents, and farming chemicals. The study found that habits that may protect against developing Parkinson's include drinking coffee or green tea; maintaining a diet rich in vitamins, minerals, unsaturated fatty acids, and flavonoids (found in many plant-based foods); and exercise.[7]

Chapters 5 and 6 of this manual discuss and promote exercise and nutrition in addition to other healthy habits.

An analysis of three major studies found a link between traumatic brain injury (TBI) and Parkinson's. The research showed that TBI involving loss of consciousness increases the risk of Lewy body accumulation, the development of Parkinson's, and the progression of Parkinson's.[8]

More about Genes and Parkinson's

As we noted in the main text, for most people with Parkinson's, there's not an identified genetic component. For some, there is, and we wanted to share more background for those in need of additional information on genes.

Researchers have identified dozens of genetic variants referred to as "susceptibility genes." These are genes that don't necessarily cause Parkinson's, but increase the risk of developing it. Variants in the *GBA* gene are the most common genetic risk factor for Parkinson's. Inherited Parkinson's can also be caused by variants of the *LRRK2*, *PARK2*, *PARK7*, *PINK1*, or *SNCA* genes. Some variants seem to be associated with greater likelihood of certain symptoms, others with faster or slower progression. These factors can also influence treatment strategies, including the consideration of deep brain stimulation (see Chapter 14).

After receiving a Parkinson's diagnosis, you may be concerned about other members of your family and whether they may be at risk of developing Parkinson's. Remember that genetic factors are causal in a relatively small number of people with Parkinson's. It's also important to know that even if your children inherit a genetic variant linked to Parkinson's, they may never develop it. As research progresses, the guidelines for genetic testing and our ability to use the results in treatment decisions are constantly evolving. That's why it's important to ask your physician what tests are available and whether they'd recommend you be assessed.

If your doctor recommends you have genetic testing, ask about genetic counseling, too. Genetic counselors help people understand the testing process and results. They also offer guidance as to how testing may influence insurance qualification and other issues you may not have considered.

PARKINSON'S AND PARKINSONISM

You had probably heard of Parkinson's before your diagnosis, but you might not have heard of parkinsonism. You may hear both terms from your physician, so understanding the difference is helpful. Parkinsonism is the term for a group of neurological conditions that have symptoms similar to those associated with Parkinson's.

For More Information: Parkinson's and Parkinsonism
dpf.org/evc-resources

Parkinson's accounts for most cases of parkinsonism. Other types of parkinsonism include progressive supranuclear palsy, corticobasal degeneration, vascular parkinsonism, drug-induced parkinsonism, dementia with Lewy bodies, and multiple system atrophy. These types of parkinsonism are sometimes called "atypical parkinsonism" or "Parkinson's plus" syndromes.

Parkinson's symptoms result from the degeneration of nerve cells in the brain. Other types of parkinsonism have different causes, such as decreased blood flow to the brain or side effects from medications that temporarily affect dopamine.

The symptoms of parkinsonism and Parkinson's are similar, so it can be difficult to distinguish from one type of parkinsonism from another. If you are experiencing tremors, slow movement, or stiffness, and wonder whether you have Parkinson's or parkinsonism, you are not alone. In fact, some people initially diagnosed with Parkinson's are later found to have another form of parkinsonism or a different condition with related symptoms. A 2025 study reviewing the cases of more than 1,600 people reported that over a ten-year period, about 13 percent saw a change in their Parkinson's diagnosis.[9]

On the other hand, people can be diagnosed with the general umbrella term "parkinsonism" when they do in fact have Parkinson's. This is most common when symptoms are mild or when the physician making the diagnosis is not a movement disorder specialist (MDS). An MDS is a neurologist who has additional fellowship training in treating Parkinson's and related conditions, including atypical parkinsonism and other movement disorders.

Art by Connie Carpenter Phinney

LEARNING THE LANGUAGE OF PARKINSON'S

The discussion of Parkinson's and parkinsonism illustrates how you will encounter a fair amount of technical language as you learn more about Parkinson's. If you find it a little intimidating, you're not the only one. Most people living with Parkinson's do not have medical training.

Try not to let all the complex words feel overwhelming. You don't need to learn everything right away. You are likely to live with Parkinson's for many years, and with time, you will continue to learn more about Parkinson's.

This manual includes a glossary for you to consult as needed (see page 352). Also, if you have a virtual assistant such as an Amazon Alexa in your home or a built-in personal assistant like Siri, you might use voice recognition to ask for guidance as you read (e.g., "Alexa, what are neurons?"). Keep in mind that that these devices can make mistakes, so consider double-checking with a different source.

> **"I've been living with Parkinson's for almost fifteen years now. I've seen a lot of cycles of good and not-so-good – let's call them speed bumps and challenges. But I'm here to say that you can still live a good life. You have to adjust."**
>
> — KEVIN KWOK, PharmD

PARKINSON'S DOCTORS AND YOUR DIAGNOSIS

A Parkinson's diagnosis is made clinically, which means it is based on the symptoms you describe and the signs your doctor or other appropriately trained healthcare provider finds during a physical exam. Diagnosing Parkinson's can be difficult, even for an experienced healthcare provider like an MDS.

Parkinson's has three "cardinal" or primary motor symptoms:

- Bradykinesia (slowness of motion)
- Stiffness/rigidity
- Resting tremor

Typically, to make a Parkinson's diagnosis, a clinician must find that you have bradykinesia and at least one of the other cardinal symptoms. This is where the difficulty comes in. These symptoms can be caused by things other than Parkinson's, including stress, medications, and injury. The cardinal symptoms of Parkinson's are also associated with other types of parkinsonism.

To help clarify an uncertain diagnosis, your doctor may consider other signs and symptoms associated with Parkinson's, including:

- Micrographia (small handwriting)
- Facial masking (reduced facial expression)
- Decreased arm swing or leg drag on one side of your body while walking

A doctor may also ask about certain symptoms you may recall having for 20 years or more. These so-called "prodromal" symptoms are known to precede a Parkinson's diagnosis in many people, and they include:

- Rapid eye movement sleep behavior disorder (RBD), described in Chapter 10
- Constipation
- Depression
- Anxiety
- Diminished sense of smell (hyposmia)

> **Looking back, I was in a pity party for about a year after I was diagnosed. I didn't spend the whole year huddled in a corner feeling sorry for myself, but I went through the motions with no drive, no goals, no purpose. I felt empty and alone. Even though I had the support of a lot of family and friends, none of them could truly understand what I was dealing with. Finally I went to a local support group meeting and there was a person in the group who recognized my struggle. She'd been living with Parkinson's for about eight years and said something very profound to me. She said, 'Look, these are the cards you've been dealt. Play your cards, and play to win.' That's when it clicked that living well was up to me. Nobody could fix me, but I could make it better."**
>
> — EDIE ANDERSON

ACCESSING EXPERTS FOR DIAGNOSIS AND CARE

Accessing care from a Parkinson's expert can be challenging. For one thing, not everyone lives in an area with an MDS nearby. For another, even in areas where there is an MDS—or even where there is a center with multiple MDS providers (many academic hospitals and medium/large cities in the United States have a movement disorder center)—it can take a while to get an appointment. This can be especially hard when you are facing an unclear diagnosis.

Fortunately, there are many good primary care provider (PCP) and general neurologists who can begin the diagnostic process with you. Not only that, but some people with Parkinson's receive great care for years from these providers and don't see an MDS often, or in some cases, at all.

Although you don't strictly need to see a movement disorder specialist, having one involved in your care can provide valuable expertise and guidance. With that in mind, many movement disorder centers have clinicians like nurse practitioners and physician's assistants who work closely with movement disorder specialists and can effectively diagnose and treat Parkinson's. These providers are also called advanced practice providers (APPs), and it is often easier to get an appointment with one of them than with an MDS, especially in busy offices.

For more about the relationship between PCPs, neurologists, movement disorder specialists, and other providers who might treat you, see Chapter 11.

WHAT DIAGNOSTIC TESTING IS AVAILABLE?

Following a review of your medical history and a physical examination, an experienced clinician will usually be able to determine if you have Parkinson's. However, there are circumstances in which additional testing may be helpful. The available diagnostic tests provide your doctor with information to help clarify the diagnosis they will make, but no test available today is sufficient on its own to determine whether someone has Parkinson's.

Reasons a doctor may order testing include recent symptom development, subtle symptoms, or symptoms that seem unusual for Parkinson's. A doctor may also consider testing if there are signs you might have a form of parkinsonism other than Parkinson's. Examples of these signs include prominent visual disturbances, frequent falls, or autonomic symptoms such as blood pressure fluctuations, bladder-control issues, or difficulty regulating body temperature.

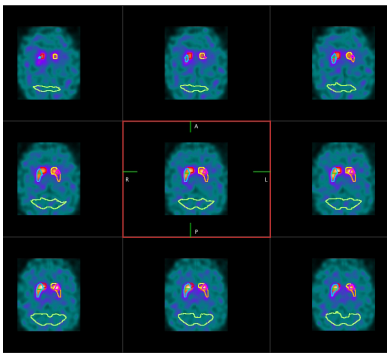
LEVODOPA CHALLENGE TEST

A drug called levodopa is the "gold standard" treatment for Parkinson's. It was one of the first Parkinson's drugs, and it is still the main drug prescribed to treat Parkinson's for most people. It is primarily used to help with slowness, stiffness, and tremor. We'll talk much more about levodopa throughout this manual.

A levodopa challenge test may help confirm a Parkinson's diagnosis by showing whether your symptoms improve while taking the medication. The test is straightforward: a physician prescribes levodopa and if the cardinal symptoms of Parkinson's you experience do not improve, you may have a different neurological condition.

The levodopa challenge test has a notable limitation: symptoms of some types of atypical parkinsonism will respond well to levodopa for a period of weeks or months before levodopa rapidly becomes less effective.

DaTscan



A brain scan called a DaTscan can help in the diagnosis of Parkinson's. This test measures the amount of remaining dopamine neurons in a part of the brain most affected by Parkinson's.

If the DaTscan imaging results show a particular pattern of decreased dopamine, the result will be considered "compatible with a diagnosis" of Parkinson's or parkinsonism. However, if the imaging results appear normal, you may still have an atypical parkinsonism—such as vascular parkinsonism or drug-induced parkinsonism—or another condition that might also look somewhat like Parkinson's, such as essential tremor.

MIBG SCINTIGRAPHY

MIBG scintigraphy is an imaging test that shows how well the heart's nerve endings are working. Because Parkinson's often causes early loss of some types of cardiac nerve endings, the test can help distinguish Parkinson's from other conditions with similar symptoms, like multiple system atrophy (MSA). Although the results of the test are not enough to make a diagnosis of Parkinson's, MIBG scintigraphy can provide valuable insight when symptoms of different conditions overlap.

SKIN BIOPSY AND SPINAL FLUID ANALYSIS

Because Parkinson's involves misfolded alpha-synuclein, it is sometimes called a "synucleinopathy." Other parkinsonisms associated with synucleinopathy are dementia with Lewy bodies (DLB) and multiple system atrophy (MSA). Specialized tests of skin samples and spinal fluid can detect the presence of misfolded alpha-synuclein.

The commercially available skin test is called the Syn-One Test. It requires a 15-minute outpatient procedure with local anesthetic. The spinal fluid analysis, known as the SAAmplify–αSYN (CSF) test, requires a lumbar puncture/spinal tap procedure. Insurance coverage for these tests varies but is becoming more common.

Right now, researchers continue to investigate how these tests may be used to distinguish between the different types of synucleinopathy. Specialized diagnostic testing for Parkinson's is rapidly evolving, so ask your provider what is currently available or may be soon if you are interested in pursuing one of these tests.

WHICH TESTS ARE RIGHT FOR YOU?

There are limits to what diagnostic tests can show, and today, tests are most often used to clarify an uncertain diagnosis. As we said earlier, Parkinson's is typically diagnosed based on a healthcare provider's observation of symptoms and a person's health history. None of the tests described in the previous section should be relied on in isolation to determine if you have Parkinson's.

Consult your medical care team to learn if any of these tests might be helpful for you. They may be expensive, so if a provider suggests undergoing one of these tests, be sure to ask why it makes sense for your specific situation and consider calling your insurance provider to determine coverage prior to undergoing testing.

> **"Don't look into the future, take one day at a time. And take the word CAN'T out of your vocabulary. You can accomplish any goal with patience and a little extra time."**
>
> — MICHELLE LANE

WHEN YOU'RE WAITING FOR A DIAGNOSIS

There are many reasons your doctor may delay offering a formal diagnosis. They may say things like, "I think you may have Parkinson's," or use a term like "clinically uncertain parkinsonian syndrome." If this is what you hear, you are not alone. While the uncertainty may be difficult, remember that a diagnosis can be hard to confirm.

If you find yourself waiting for test results or an available appointment, there are many productive things you can do in the meantime. The best course of action depends on the challenges you're facing.

- Exercise can help with anxiety. It's also good for improving health and decreasing Parkinson's symptoms. It's never too early to start or recommit to exercise.
- If you are experiencing difficult emotions like anger, fear, or sadness, consult with a mental health professional. Your insurance provider, your doctor's office, or a local Parkinson's organization should be able to recommend one.
- If your doctor has recommended diagnostic testing such as the options discussed above, learn more about the available tests.
- If you want to talk with someone who knows about navigating a Parkinson's diagnosis, reach out to a local Parkinson's organization. Support groups often welcome people without a formal diagnosis. Chapter 15 of this manual is all about

- community and is a good place to start. You can also reach out to a Davis Phinney Foundation Ambassador. Our more than 150 Ambassadors are people who are living with Parkinson's, care partners, and others who make themselves available as volunteers to provide support and answer questions. Scan the QR code on this page or visit our website, **dpf.org**, to connect with one.

For More Information: Davis Phinney Foundation Ambassadors
dpf.org/evc-resources

These are just a few potential ways to manage a waiting period. They all involve being proactive, learning, and connecting with others. One of the most important things about living well with Parkinson's—whether you are still waiting for a confirmed diagnosis or you've been living with it for decades—is to focus on connection, action, and activity.

PROVIDER BIAS

There are many valid medical reasons why the process of diagnosing Parkinson's can take a long time. Unfortunately, research has also found that provider bias based on gender, sex, age, or race may be a factor in delayed diagnosis and referrals.

The key is to remember that you are the best advocate for you. If you or your care partner feel you are not being heard by your doctor, seek a second opinion. Parkinson's affects every person and every population differently, and additional considerations for women, people of color, high-risk groups, and people diagnosed before age 50 are discussed in Chapter 2.

HOW DOES PARKINSON'S CHANGE OVER TIME?

Parkinson's diagnoses can change because symptoms evolve over time. A symptom might initially suggest *Parkinson's* to your doctor, but indicate *progressive supranuclear palsy* if that symptom worsens.

> **In the beginning, I really didn't have a whole lot of challenges. Now, a decade into living with Parkinson's, I have to be really cognizant of sleep, my schedule, and medicine. If I'm not, I might be okay today, but I'll have an off day tomorrow. I need to manage Parkinson's more hands-on and consciously.**
>
> — STEVE HOVEY

Changing symptoms can make anticipating what will come next a source of anxiety, fear, or frustration. This is one reason that physicians are reluctant to try to predict the exact course of Parkinson's or how severe or mild your symptoms will be.

Every person's symptoms change at different rates and may be experienced in a variety of ways. In fact, although Parkinson's is progressive, some of your symptoms may become less difficult to live with over time as you learn how to manage them.

With all this variability, there are two important things to know:

- Parkinson's symptoms typically evolve slowly, so you are unlikely to wake up one day with an entirely new, highly noticeable, and disruptive symptom. If you do experience a sudden substantial change, it could be caused by something else entirely, like an infection, and you should talk with your doctor.
- Your experience of Parkinson's will be unique, so try to avoid forecasting based on what you hear about someone else's experience.

It is also true that there are similarities in what most people with Parkinson's experience over time. In the initial stages, symptoms such as tremor, slowness, and rigidity typically begin on one side of the body, spreading to the other side over time. Walking, speech, or swallowing problems can also occur, though these symptoms usually progress over many years. For most people with Parkinson's, balance problems tend to occur in later stages, years after diagnosis. If you start having balance problems, be sure to talk to your doctor.

How your Parkinson's progresses and the different symptoms you experience are specific to you. Consulting this manual from time to time will provide you with actions you can take to address your symptoms and their evolution.

STAGES OF PARKINSON'S

Doctors use many tools to assess Parkinson's symptoms. Some of these tools are also used to determine what "stage" of Parkinson's a person is in.

Commonly used systems include the Unified Parkinson's Disease Rating Scale (UPDRS) and the Hoehn and Yahr scale. Researchers are also investigating biomarkers—measurable aspects of a person's biology that can help determine how advanced their Parkinson's is—as another way to evaluate and determine "stages" of Parkinson's. All evaluation and rating systems used in Parkinson's are complicated, and their meaning and usefulness is sometimes debated.

Because of the ongoing discussion about rating scales and stages, we won't go into detail describing them here. Instead, to provide a practical overview of life with Parkinson's, we will discuss the most common symptoms of Parkinson's in three groupings.

Think of this breakdown as providing a sense of what Parkinson's might look like over time, not as a definitive timeframe of when you'll experience any particular symptom. It's worth saying again: your experience will be unique, and you may have any of the symptoms named below in a different order. It's also possible you may never experience some of them. In Chapter 2, we'll go into greater depth about how Parkinson's might affect you over time.

This first grouping contains symptoms and experiences of Parkinson's that are common around the time of diagnosis:

- Symptoms on one side of the body
- Decreased arm swing on one side when walking
- Decreased stride length
- Dragging your foot while walking or scuffing your toes while walking, especially when tired
- Changes in leg coordination when cycling or running
- Sense of muscle fatigue or heaviness in your arm or leg on one side of the body
- Trouble with hand coordination, especially on one side (this becomes apparent in tasks that use both hands, like washing your hair or typing)
- Reduced range of motion in your shoulder, shoulder pain, or frozen shoulder
- Decreased sense of sense of smell (hyposmia)
- Sleep issues, including vivid dreams or acting out your dreams
- Mask-like face or change in facial expression (hypomimia)
- Smaller handwriting (micrographia)
- Neurogenic orthostatic hypotension (nOH, see Chapter 10)
- Constipation

As time passes and your Parkinson's becomes more complex, you may experience some of the symptoms in the next grouping:

- Symptoms on both sides of the body
- Soft speech (hypophonia)
- Mild swallowing problems, such as difficulty swallowing pills
- Flexed or bent posture and shuffling gait that can lead to balance challenges
- Urinary challenges
- Increased daytime fatigue and/or daytime sleepiness

- Fluctuations in the intensity of motor and non-motor symptoms and how well medications treat these symptoms
- Difficulty with multi-tasking
- Changes in vision

Around the time your symptoms become more complex, you may also experience dyskinesia: involuntary muscle movements such as wriggling, head bobbing, or swaying. Dyskinesia is not a symptom of Parkinson's, but a side effect of treatments that impact the levels of dopamine in your body, including the most common Parkinson's medication, levodopa. There's much more on dyskinesia in Chapter 12, which focuses on medication management.

This last group contains experiences most likely to occur years after your first symptoms developed (if they occur for you at all):

- Postural instability with significant balance problems and frequent falls
- Rigidity in the neck and torso/trunk causing difficulty in turning and rotating
- Significant challenges with walking, including episodes of feeling stuck to the ground
- Significant speech and swallowing problems
- Drooling
- Advancing cognitive issues and trouble with executive function/decision making
- Dementia (See Chapter 8—Parkinson's dementia is distinct from other types)
- Hallucinations and delusions (See Chapter 8 for specific information about these experiences)

As your Parkinson's evolves, it is important to keep your medical care team informed of what you experience so they can help you manage changing symptoms. In advanced stages, feedback from a care partner or caregiver may play a bigger role, as self-reporting your symptoms might become more difficult.

At every point along the way, you can take action to maintain a high quality of life. Advocate for yourself during appointments, ask for referrals to other specialists, be open to considering new exercises and therapies when they're recommended by a specialist, and take time for self-care.

Today Is the First Day of the Rest of Your Life (with Parkinson's)

By Benzi Kluger, MD, MS, FAAN

I have a confession to make. I am a neurologist. Please do not hold that against me. While I am not a person with Parkinson's, I have worked with hundreds of people living with it. I am also a pretty good listener. When I finished my training in 2008 and began seeing patients on my own, I learned from people living with Parkinson's and their families that there were three very important lessons about it that were not part of my training.

First, *having Parkinson's sucks!* It might surprise you that doctors were not taught this simple fact, but it's true. In fact, many neurologists believed (and still believe) that having Parkinson's is good news because there are treatments available for many symptoms. Many neurologists persist in this error because they don't have Parkinson's, haven't let themselves imagine what it's like to have it, and haven't cared for people in the most advanced stages of it when the suckiness is undeniable.

When I learned to ask people, "What's the toughest part of Parkinson's for you?" I learned that it was rarely just the tremor or slowness. It was the inability to do things they used to enjoy, the changes in how people treated them, the fear of what's ahead. In my field of palliative care, we talk about the "total pain" of illness to remind ourselves of all the dimensions of life—physical, emotional, social, and spiritual/existential—impacted by illness.[10] To make life better, it helps to talk about what sucks.

When you acknowledge what sucks, you can deal with it. Sometimes there are ways to treat the symptoms, sometimes ways to adapt your activities, sometimes ways to better cope or find community. At all times, in all things, and when all else fails, don't forget compassion and self-compassion, the art of holding gently what's crying out (or whispering) to be held. Sometimes what sucks feels overwhelming, and being overwhelmed, we are fooled into thinking that it is too big and scary to deal with. *This is often when it helps to ask for help, and to let go of going it alone.* You might turn to a partner, family, friend, therapist, chaplain, pastor, or a higher power. But it all starts with being willing to talk about what sucks—and with finding people who know how to listen and make you feel seen and heard.

Second, *it is possible to live—not just survive*—with Parkinson's. While, from the outside, people often think I have a depressing job, I don't feel that way at all. I am constantly inspired by patients' grace, humor, inventiveness, strength, courage, wisdom, hope, and love. In my clinic, I am explicit in making space to deal with what sucks and to not lose sight of the fact that meaning, love, joy, and many other wondrous things are often still possible despite having a crappy illness. Some questions that may be worth asking include, "How have I made it through tough times in the past?", "How could I make this week (or today) five percent better (more relaxing, more peaceful, etc.)?", and, "How would I like to grow through this illness?"

In a talk I give to neurologists, I say that love, joy, and meaning are secret weapons that allow us to steal victories from incurable illnesses.[11] Part of this talk is about "total enjoyment of life": to make sure we are as thorough in exploring opportunities for joy as we are with sources of suffering.[12] This includes physical pleasure (holding hands, eating ice cream), emotions (watching a comedy, listening to music), social enjoyment (spending time with friends or family), and spiritual fulfillment (centering prayer, spending time in nature). Regarding the spiritual, this need not be religious or complex. By spiritual, I simply mean how you find and express meaning, connection, and choice. Where you find peace and transcendence.

The other part of this talk is about moving from a problem list to a goals list. This can be a subtle but powerful shift. Instead of putting your energy toward trying to get rid of pain (or other symptoms) and hoping that your life improves, you direct your energy toward improving your life and figure out what symptoms need to be managed to get you there. For example, rather than taking a pain medication around the clock, you might take it three times a week, 30 minutes before your dance class, so that you can reclaim this important part of your life.

Finally, *the future of Parkinson's care is in the hands of people living with Parkinson's*. Although you might not feel this way, you already know more about living with Parkinson's than 99 percent of the experts. You definitely know more about living with Parkinson's than I do. That's why, when I do research, I make sure to have a group of "lived experience experts" (a.k.a. patients and their family) advising and guiding me to make sure that we are asking the right questions and developing models of care that actually move the needle on making life more livable. I encourage you to step into this role as a lived experience expert. Whether or not you get involved in research, education, advocacy, or becoming a Davis Phinney Foundation Ambassador, you have the opportunity to speak up

and to make care better for yourself and the people who come after you. You can do this in the way you prepare for doctor visits, in the questions that you ask your healthcare team, in the way you present yourself to family and friends.

I wish you peace, hope, love, and joy on your journey.

Benzi Kluger, MD, MS, FAAN, is the founding director of the Palliative Care Research Center and Neuropalliative Care Division at the University of Rochester Medical Center, where he is also a professor of neurology and medicine. A pioneer in neuropalliative care, a field dedicated to the radical idea that improving the lives of persons affected by neurological illness requires seeing and treating them as whole people, Dr. Kluger created one of the first team-based neuropalliative care clinics in the world at the University of Colorado and has published numerous papers important to the growth of this field. His research focuses on neuropalliative care, fatigue, and neurodegenerative illness with excursions into other areas, including nutrition, acupuncture, and cannabis. Visit him at BenziKluger.com and @BenziKluger on social media.

CHAPTER 2 // PARKINSON'S AND YOU

OVERVIEW

Because *anyone* can be diagnosed with Parkinson's, before we turn to day-to-day living, this chapter recognizes that people of many diverse backgrounds live with Parkinson's.

Millions of people around the world live with Parkinson's and all are in a club no one asked to join. They have different lives, jobs, traditions, families, and points of view. While there are some commonalities in the experience living with Parkinson's, there are also many things that will be distinct based on your personal background and individual experience.

In Chapter 2, we'll discuss:

- How the stereotype of Parkinson's as an "elderly white man's condition" has created stigma and ignored the real experiences of many people with Parkinson's
- What women, people of color, those diagnosed before age 50, and people with long-term exposure to risk factors might encounter
- How symptoms of Parkinson's may change over time and tips for how to manage this
- How you can work against stigma, take care of your whole self, and start—or continue!—to live well today

WHO GETS PARKINSON'S?

Parkinson's is the fastest growing neurodegenerative disorder in the United States and the second most common behind Alzheimer's. Today, it affects between 1 million and 1.5 million people nationwide. More people are living with Parkinson's in the US than live with multiple sclerosis, muscular dystrophy, or amyotrophic lateral sclerosis (ALS) combined.

It is estimated that nearly 90,000 Americans are diagnosed with Parkinson's each year—a 50 percent increase from earlier estimates.[13] This is approximately one person every six minutes. More than 11 million people are estimated to be living with Parkinson's around the world.[14] Other noteworthy statistics include:

- Men are approximately twice as likely as women to be diagnosed with Parkinson's; it may affect a greater share of women in Asia.
- Most people living with Parkinson's are 60 years or older, but 5 to 14 percent are diagnosed before age 50 and have young onset Parkinson's (YOPD).[15]
- Another way to look at it is that 1 percent of all Americans over 60 are living with Parkinson's. The figure increases to 5 percent of the entire American population over age 85.

The statistics above don't tell the whole story. For one thing, many people—especially those living in areas with no movement disorder specialists or neurologists—have symptoms for a long time before they receive a Parkinson's diagnosis. Women and people of color may be more likely to experience delays in diagnosis.[16, 17]

People with YOPD also tend to have a delay between when symptoms start and when they are diagnosed. There are many possible explanations for this, but two common ones are that symptoms can be harder to notice in younger people and that doctors are less likely to think of Parkinson's when examining a person in their 20s, 30s, or 40s. Both factors likely contribute to people being under 50 when they notice symptoms, but over 50 at the time of diagnosis.

In other words, while the available statistics give a high-level picture of who gets Parkinson's, the reality is that Parkinson's affects people of all backgrounds, and the experiences of people with different backgrounds vary for a wide variety of reasons.

GETTING THE CARE YOU NEED

For many years, the conventional image of Parkinson's—even in medical literature—was an older white man with stooped posture. Limited and incomplete conceptions of what Parkinson's is and who it affects have led to a poor understanding of the unique challenges faced by those who don't match the stereotype.

The sections in this chapter on people of color, women, younger people, and high-risk communities are meant to equip you with information for the challenges you and others impacted by Parkinson's face. This may seem overwhelming, but know that you are not alone, that the Parkinson's community has been working to call attention to disparities and diverse concerns, and that you can get the care you need. It may require you to be a strong, informed advocate for yourself. We hope this manual will help you along the way. Additional resources are available on our website.

PEOPLE OF COLOR AND PARKINSON'S

Multiple studies have found that fewer people of color are diagnosed with Parkinson's and receive treatment for it than would be expected based on population sizes. These disparities are driven by a complex mix of socioeconomic barriers, unequal access to neurological care, and biases within healthcare systems.

A 2020 review highlighted studies that found Black Americans living with Parkinson's were less likely to be prescribed medications, receive a physical therapy referral at their first appointment, and qualify for disability protections or benefits—even with similar exam results.[18] A landmark study published in 2009 found that "African-Americans were still half as likely" as white Americans to be diagnosed with Parkinson's due to a variety of geographic, economic, and social barriers.[19]

> **When I was first diagnosed, I searched for African Americans with Parkinson's and only found my sister Caroline and Muhammad Ali. It was frightening to think I might be one of the few African Americans affected by Parkinson's. I soon realized how little information existed about Parkinson's in the African American community or about African American providers working in the field. Early on, I learned the importance of building a strong care team. With the support of my wife April, I've been blessed to create a team—my neurologist, physical therapist, and Rock Steady Boxing coach—all African Americans, united by a common passion and shared goals that help me live well."**
>
> — RON SMALL

Less research has focused on the Hispanic community in the US, but the largest study of this population to date, published in 2023, found more frequent YOPD, worse symptoms, medication doses that were too low to control symptoms, and shorter lifespans.[20] The cumulative effect of these disparities likely contributes to higher rates of depression and cognitive impairment observed in some studies of Hispanic people living with Parkinson's.

There are differences in the rate at which people of color in the US access specialized medical care for Parkinson's. For example, Black, Hispanic, and North American Native Medicare beneficiaries living with Parkinson's have been found to access care from Parkinson's specialists at approximately half the rate of white Medicare beneficiaries.[21] Globally, the situation can be even more troubling. The World

Health Organization reports that low- and middle-income countries—including much of Africa, the Middle East, and South Asia—face significant shortages of Parkinson's therapies, with essential medicines often unavailable or unaffordable and access to neurologists limited.[22, 23, 24]

Lack of representation magnifies the effects of stigma and social isolation, which can lead to worse health outcomes. Also, when clinical trials don't include diverse groups, the results are less relevant for every person living with Parkinson's.

WOMEN AND PARKINSON'S

While people with Parkinson's often experience many of the same symptoms, some studies suggest that women may face a greater burden than men do from certain symptoms.[25] The reasons for this are not fully understood. Women's symptoms are sometimes underrecognized or taken less seriously, which can lead to delayed diagnosis, under-treatment, and more pronounced effects on daily life.

Research has shown that women with Parkinson's tend to experience more tremor, dyskinesia, anxiety, depression, apathy, fatigue, and pain than men. Women with Parkinson's also tend to have greater psychological distress, more difficulty with self-image, and more frequent self-reported disability.[26] Conversely, they often have less rigidity, fewer cognitive symptoms, and fewer gut-related changes. Women are also more likely to be diagnosed later and face longer delays between when they first see a doctor about their symptoms and when they receive a diagnosis—differences that may stem from biological factors, social expectations around caregiving, or differences in how healthcare providers perceive and respond to their symptoms.

These diagnostic challenges are compounded by treatment disparities. Like people of color, women are less likely to be referred to physical therapy. According to a survey of women with Parkinson's, 9 in 10 women said neurologists did not discuss the impact of hormones on their Parkinson's. More than 8 in 10 said their symptoms were worse the week before they menstruated and two-thirds said their symptoms worsened after menopause.[27]

Societal and emotional effects may be different following a diagnosis, as well. Women report higher levels of stress; higher rates of disability; and lower levels of social support, including from their partners. Other challenges include negative self-image and loss of sense of femininity, as well as increased feelings of isolation and not being heard by friends, family, and healthcare providers.

The situation is often even more complex when a woman is diagnosed with young onset Parkinson's (YOPD). Women with YOPD often experience challenges

related to contraception, menstruation, pregnancy and childbirth, menopause, and hormonal changes.

> **I found a support group of women with Parkinson's that met virtually, and it has been the blessing I needed! Thanks to the education and support from other people with Parkinson's, I have been able to overcome my fear and move forward. Now, as a Davis Phinney Foundation Ambassador, I also support, listen to, and give hope to other 'parkies' like me!"**
>
> — NICOL WALSH

HIGHER-RISK COMMUNITIES AND PARKINSON'S

Some people have a higher risk of Parkinson's because of their military service, job, or where they lived—not because of their genetics or background.

Veterans are more likely than the general population to be diagnosed with Parkinson's due to chemical contact on base or in the field, including exposure to the Vietnam War-era herbicide known as Agent Orange and a degreaser used on engines called trichloroethylene (TCE).[28] Higher rates of traumatic brain injury are also a factor. The US Department of Veterans Affairs (VA) serves 110,000 people with Parkinson's.

Because the VA is America's largest healthcare system, and because veterans have robust social and professional networks all over the country, veterans with Parkinson's have access to a range of resources, including the VA's six highly regarded Parkinson's Disease, Research, and Clinical Centers (PADRECCs).

Agricultural workers and rural families are also diagnosed with Parkinson's more often because of exposure to chemicals, including several pesticides that have been linked to higher rates. Further, because these chemicals last a long time and seep into wells, the 43 million Americans who drink private well water are also at higher risk, regardless of whether they live or work on a farm.

People working in certain environments or living nearby appear to be at higher risk. Research has shown a link between Parkinson's and the chemicals TCE and perchloroethylene (PCE), which were once widely used in dry cleaning.[29] Studies also link welders, firefighters, rubber and plastics workers, and miners to higher rates of

Parkinson's. Emerging research is assessing the risk of everything from factory air pollution to living near golf courses aggressively treated with pesticides.

YOUNG ONSET PARKINSON'S DISEASE (YOPD)

Those diagnosed with Parkinson's before age 50 have young onset Parkinson's (YOPD), which is sometimes called early onset Parkinson's. The emotional, social, physical, and psychological needs of people diagnosed with YOPD are different from those diagnosed at an older age. YOPD is more often linked to genetic causes than Parkinson's diagnosed later in life.

Photo by Christy Gonzalez

For many people with YOPD, symptoms progress more slowly and present differently than symptoms experienced by those with older onset Parkinson's. For example, initial symptoms for YOPD are often rigidity and painful muscle cramps or dystonia, while initial symptoms for older onset Parkinson's are most often tremor and instability/balance problems.

Motor symptoms of both young and older onset Parkinson's typically respond well to medication. Over time, motor complications—like medication-induced dyskinesia and having symptoms return as one dose of medication wears off but before another dose kicks in (see Chapter 12)—can become a problem earlier in the disease progression for people living with YOPD.[30] These impacts also tend to be more severe in YOPD.

> **"Especially when you have young onset Parkinson's, you realize so clearly that life is short. Because of Parkinson's, I act more quickly. Let's take that trip. Let's do that move. Let's retire way before we ever thought we would. The value of living fully right now is something that we as a family have really emphasized."**
>
> — JILL ATER

Despite earlier problems with motor complications, people with YOPD tend to have slower rates of cognitive decline and develop Parkinson's disease dementia (PDD) less frequently than those with older onset Parkinson's.[31]

People with YOPD typically live with Parkinson's for many years and must find ways to adapt to its effect on their lives. Some will focus on adjusting to changes in physical

abilities, but many people with YOPD find that coping with the impacts of Parkinson's on work, hobbies, family, and relationships is more difficult.

People with YOPD also often face the difficult task of juggling a career, family life (including parenthood and caring for aging family members), and changes affecting activities that may be the foundation of personal relationships. The stigma surrounding social expectations and isolation can be particularly distressing.

For More Information: Young Onset Parkinson's Disease (YOPD)
dpf.org/evc-resources

Managing the chaos of prime adulthood can be challenging, but it can also highlight strengths and positive aspects of who you are. This requires prioritizing yourself and your well-being as well as staying connected with others. It is critical to pay attention to all aspects of your health, including your mental health, and many people with YOPD find that it helps to seek support from a mental health professional early on.

Amid all that comes with young onset Parkinson's, know that you can affect how your experience of Parkinson's changes over the years, and this manual can help. Keep it handy and refer to it as needed. The Davis Phinney Foundation's website has a section dedicated solely to YOPD with videos, advice, webinars, and YOPD spotlights.

PARKINSON'S SYMPTOMS AND YOUR EXPERIENCE

This manual has already mentioned many symptoms of Parkinson's and explained that each person will have a different experience. Detailed information is found in Chapters 7 through 10, but to understand how Parkinson's might affect you, it's important to understand Parkinson's symptoms a little more broadly.

Although it is called a movement disorder, Parkinson's has motor symptoms (movement symptoms, detailed in Chapter 7) and non-motor symptoms (related to thinking, emotions, or automatic bodily function, described in Chapters 8, 9, and 10). Researchers and others in the Parkinson's community use these terms, but many non-motor symptoms, such as constipation, fatigue, and pain, also involve movement. Symptoms like these are sometimes called "hybrid symptoms."

While the motor symptoms of Parkinson's are often more familiar and more noticeable to others, many people living with Parkinson's report that the non-motor symptoms are more challenging than motor symptoms. Of course, what is extremely difficult for one person may not bother another person much at all, so try to avoid forecasting your path

with Parkinson's based on someone else's experience. Don't start living today in a future that may not be yours.

The unpredictability of the changes described above frustrates many people. Over time, however, you will become skilled at pivoting when symptoms change. The key is to stay open to getting help and to learning new ways to manage symptoms as they arise and evolve. With attention, diligence, and a strong team helping you, you can find new ways to manage your symptoms.

LIVING WITH PARKINSON'S OVER TIME

Everyone reading this book who is living with Parkinson's will have been doing it for a different amount of time and will have had a unique set of experiences. However, drawing on our two-plus decades of making every victory count and more than 15 years of publishing and updating this manual—work informed by people just like you—we have identified a few patterns in the experiences people with Parkinson's tend to have over time. We'll share some of them below.

In Chapter 1, we listed some common experiences and symptoms of Parkinson's. Below, we'll talk about many of those same experiences. Our intention is to add more depth by describing how these experiences may impact your life and how you can respond in a productive way.

Reading this section may be challenging at times, as it describes some of the difficult symptoms and changes you might experience. Although what follows focuses on symptoms and how you might approach managing them, there is another takeaway from this section if you read between the lines: it may sound surprising, but many people do find that Parkinson's helped them change their life for the better.

Many people find they become more self-aware, kinder, more willing to ask for help, more physically active, or more open to trying new things. It's also common for people to reprioritize old friendships and build new ones, often with people in the Parkinson's community. People say that as time has passed after their diagnosis, they've become someone they're prouder of and someone they like a little better.

> **"When I was diagnosed with young onset Parkinson's, I chose to be bold, stay active in my life, and educate myself and everyone around me about Parkinson's. I knew that a cure was not waiting for me right now, but the more I educated people, the more people would rally to support our community."**
>
> — GREGG BUSCH

EARLY LIFE WITH PARKINSON'S

Early in life with Parkinson's—especially shortly after diagnosis—you might experience acute fear, depression, or even dread as you process your diagnosis. You might also find that you feel different about the world and your place in it: many people with Parkinson's struggle with social expectations and stigma, the feeling of being negatively judged by others because of their symptoms and diagnosis.

These experiences are part of why the early stage of your life with Parkinson's is a valuable period for connecting with friends and family and strengthening your support network. It's never too early to reach out to a physical, occupational, and/or speech therapist. Having a baseline assessment with these care providers can help measure changes later. Early in your life with Parkinson's is also a great time to grow your community and find a mental health professional to work with. Connect with people with Parkinson's and people without Parkinson's and do the things you enjoy with them.

Exercise truly helps, and in the early days of living with Parkinson's, many people start new exercise regimens, whether or not they were active exercisers before. As we'll discuss in Chapter 5, exercise can decrease the impact of symptoms, increase social engagement, and potentially even slow the progression of your Parkinson's. If you take anything away from this book in these first chapters, let it be this: exercise is one of the most important and powerful treatments for Parkinson's.

Exercise is also one of many areas where it's good to get expert advice early. A neurologic physical therapist (neuro PT) should be one of the first specialists you contact after a diagnosis and someone you consult annually after that. The Academy of Neurologic Physical Therapy, **neuropt.org**, is a great resource for finding a neuro PT.

In the days, months, and even years following a Parkinson's diagnosis, some people find their symptoms are mild enough that medication is not necessary for them to do everything they want to do. In fact, this is a good touchstone to use when thinking about medication: if Parkinson's is stopping you from doing what you want to do, it's a good time to talk with your doctor about starting or changing medications.

MID-LIFE WITH PARKINSON'S

People with Parkinson's often experience a shift in their symptoms after a few years, when managing symptoms starts to involve multiple types of medication and the effectiveness of those medications starts to vary.

This can be hard for several reasons. A big one is that your ability to do what you want, when you want, may be less reliable. This may impact your relationships, your work, your hobbies, your mood, and even your sense of who you are. Because you will have already worked hard to adapt, these new challenges can be confusing and emotionally difficult.

This is especially true for how the evolving challenges affect your relationship with others—and with yourself. Try not to let this become overwhelming. Talk to your doctors, your care partner, your family, and your friends. Be as open as possible about your experience, and if you don't have a mental health professional on your care team, now is the time to find one.

Another hallmark of the middle part of life with Parkinson's is that it may more significantly affect your balance and ability to walk. When this happens, talk to a physical therapist. This can also be the time to reach out to an occupational therapist (OT). OTs help people with daily tasks at home and elsewhere when a health condition makes those tasks harder. Making even small adjustments at home, like moving furniture or rugs, can result in big improvements to home safety and quality of life.

For those who are still working, this time of life with Parkinson's may involve deciding to retire or to change jobs. Considerations to weigh include financial planning, downsizing, and other lifestyle changes to live comfortably—and safely—in the future. During this time, you may also face the difficult decision of whether you should stop driving. An OT can also help with this decision.

You might also start noticing impacts to your swallowing, your speech, and your thinking—especially word recall and multi-tasking. These experiences tend to be mild and change slowly over time, but it's never too early to talk with your doctor about them. The doctor may recommend you add a speech-language pathologist or a neuropsychologist to your care team. To learn more about your care team and the experts you should have on it, see Chapter 11.

In addition to being a time in which you're likely to have changes to your medication regimen and add more experts to your care team, you may start hearing more from your doctors about interventions like medication infusion pumps, focused ultrasound, and deep brain stimulation. For more on these therapies, turn to Chapter 14.

ADVANCED PARKINSON'S

Living well with advanced Parkinson's won't look the same as living well did earlier in your life with Parkinson's However, with careful planning and deliberate action, less of your time will be spent managing the deep challenges of Parkinson's, and more of it will be spent at peace, in comfortable, familiar settings, with the people you love.

There is not a universally agreed upon definition of advanced Parkinson's, but generally speaking, it is when your symptoms start to significantly limit your ability to care for yourself without assistance. Daily tasks evolve from minor difficulties into true challenges or impossibilities. Balance and walking issues may regularly call for a walking aid or wheelchair. Speech and swallowing issues could require changes to your diet or limit your

ability to converse reliably, resulting in social withdrawal. You may be unable to get out of bed or raise yourself from a seated position without assistance. Trouble following multi-step directions or processes could limit your ability to do a lot of what you used to do around your home.

During this time, things might become more tense in your household. There will be much more stress on your care partner. For additional support, read Chapter 4 of this manual or find additional care partner resources on our website.

For More Information: Care Partner Resources
dpf.org/evc-resources

Specialists can suggest changes to help you and your care partner, but only if you're all on the same page. It is critical for you to do your best to clearly and accurately communicate with your care team. Advanced Parkinson's symptoms may make this challenging, so use your support network to help you explain the problems you face.

At some point, you may have conversations about downsizing or moving to a live-in care facility. Those who are able to avoid this—or require it only for a brief period at the end of life—are often those who made significant modifications to their home life in collaboration with an occupational therapist or family advisor earlier in their life with Parkinson's. Similarly, many people tell us they found regular time with a mental health professional extremely helpful in this part of life with Parkinson's.

This can be a very difficult part of Parkinson's, so it's a good idea to talk with your family about your plans and preferences as early as possible. A mental health professional is extremely helpful at this stage, as navigating the advanced Parkinson's requires a whole-team effort. With preparation, open communication, and an awareness of the resources that are available, many people with Parkinson's continue to live well despite the challenges of advanced Parkinson's.

> **I talk with care partners all the time, and they're like, 'Why do those terms ['hospice' and 'palliative care'] have to go together? They are not the same thing. Palliative care is that comprehensive, quality-of-life–focused care for anyone with a serious illness, regardless of age… and it can coexist with curative treatment if we have it.'"**
>
> — JORI FLEISCHER, MD

CHAPTER 15 // FINDING COMMUNITY

OVERVIEW

The second half of this manual provides much necessary information about symptoms and medications. As we close the book, we echo what Davis Phinney wrote about the importance of a whole-person approach to living well and the importance of being proactive, maintaining optimism and hope, and connecting with community: "It requires accompaniment, or as my Spanish-speaking friends say, *acompañamiento*, the experience of not walking this path alone, but together."

This chapter discusses the importance of community in all aspects of life with Parkinson's and how you can make meaningful connections in rich and varied ways.

In Chapter 15, we'll discuss:

- What makes a productive support group and how to find one
- How clinical trials work and how they can connect you to others in unique ways
- What leaders at the Davis Phinney Foundation, Parkinson Canada, and Fight Parkinson's in Australia have learned in their communities
- How learning in community can help you live well
- How the Olympic spirit and teamwork are essential to living well with Parkinson's

Each person with Parkinson's has their own life experience and their own experience of living with Parkinson's. Being in community gives us the opportunity to exchange knowledge and wisdom to help each other and anyone affected by Parkinson's. Making these connections is a source of emotional support, hope, and even plain and simple fun.

We encourage you to connect, both with your Parkinson's community and with other communities you're a part of. We are stronger together.

> **"The best thing I could do to accept my diagnosis was to get involved in activities within the Parkinson's community. I have met wonderful people who will be my friends for the rest of my life. Their stories have encouraged me to tell my story, which is something you can't really do unless you accept it."**
>
> — CAROL CLUPNY

FINDING AND MAKING THE MOST OF A SUPPORT GROUP

A good support group—whether local or online—can help you in many ways. In Chapter 4, we discuss the importance of avoiding social isolation, but there is much more to say about the benefits of connecting with people who understand life with Parkinson's.

In a support group, you meet others who have gone through what you're going through, from doctor's appointments to medication adjustments and from relationship changes to trial and error in diet and exercise. You can learn from members of a support group. You can also laugh with them, cry with them, and be yourself with them. Ask around. People in our community will tell you it adds up to a lot.

FINDING A SUPPORT GROUP

In addition to support groups supported by well-known national and international Parkinson's organizations, there are smaller organizations operating at the state, regional, and local levels that host both online and in-person support groups. In the United States, you can find some of these organizations through an alliance called the Independent Parkinson's Network.

Parkinson's-focused organizations are not the only places to find Parkinson's support groups. You can also find these groups through local hospitals, neurologists' offices,

physical therapists' offices, Area Agencies on Aging, senior centers, veterans' service centers, and churches and other houses of faith.

If you're having a tough time finding a group that meets your needs, ask around: many more people are connected to Parkinson's than you may think. For example, your pastor or other faith leaders might know of community connections you might not be aware of. You can also check with local senior centers or public recreation departments, your pharmacist, a social worker at a medical office you visit, or a community health worker (known as *promotores* in the Hispanic community). All of these can be great sources of local information, and they are just a few of the places you might look.

> **"A couple of months after my diagnosis, I attended a Davis Phinney Foundation event and discovered a women's support group through a small local nonprofit. The group met by phone, which fit my busy schedule and eased my anxiety about meeting others with Parkinson's. Before long, I became a co-facilitator, and when COVID hit, we moved onine. To call this group my lifeline is an understatement. The women are incredibly diverse—retired and working, single and married, cisgender and LGBTQ+—but when we come together, none of that matters. We care for, encourage, and celebrate each other. This group has been an absolute blessing—something I never would have found without Parkinson's and the Davis Phinney Foundation."**
>
> — NICOL WALSH

MAKING THE MOST OF A SUPPORT GROUP

Finding a group is just the start. Every support group has its own character and focus, and there's no one-size-fits-all solution. Each member of a group influences how the group feels and what meetings are like, so be careful about giving up on a group that might not seem like a match after just one or two meetings. For one thing, your presence will influence the group. For another, every member doesn't attend every session. Give it some time.

Some support groups focus on specific topics like DBS. Others are built around shared experience. For example, there are young onset groups, groups for those who are newly diagnosed, and groups for women or men only.

If you aren't happy with a group, take a moment to consider why. It could point you in the right direction if you decide to find a different group. Of course, it's always possible to start your own group, too. If you're not finding the right fit, maybe it's time to get creative and start something new.

FINDING COMMUNITY-BASED EXERCISE OPPORTUNITIES

Sometimes, a support group that just talks about Parkinson's can feel a bit stuck in its ways, and the conversation may become unsatisfying or stagnant. Another source of community can be a Parkinson's group that meets to work out. Exercise is a compelling activity to consider since moving your body is vital to living with Parkinson's (see Chapter 5). Plus, a little "peer pressure" in the form of an exercise group that expects you to stop by might make it easier to stick to your workout goals.

You can join an established program like Pedaling for Parkinson's™ and Rock Steady Boxing. Or you can just meet friends at a park for a regular Saturday morning walk. Formal or informal, it doesn't matter. Whatever gets you moving and socializing is good. Not only do exercise-focused groups help make exercise a habit for everyone in the group, they also foster deep bonds through a challenging and fun shared activity.

There are countless ways to exercise, and changing activities from time to time keeps the experience fresh and engaging. Don't be afraid to push an exercise-based group to try new activities: tai chi, weight training, ping pong, swimming, dancing, rock climbing, pickleball, and walking soccer are just a few of the types of exercise you might not have tried that have been researched and found beneficial for people with Parkinson's. There are likely people in your community who would enjoy being part of something new and could be sources of great inspiration and strength for any group.

> **Not only does exercise help Edie with her Parkinson's, it has helped me a lot. We both encourage each other and get to know each other better. It's always encouraging when you see your partner working hard, no matter how far the disease has progressed."**
>
> — SCOTT ANDERSON

If there isn't an exercise group in your area or if you need an expert to help design and lead your workouts, there are few things you can do. Contact a gym or your local YMCA to see if they have any instructors who have interest in or experience with Parkinson's. It's possible someone is available but you just don't know it. You can also talk with an established program like the ones we mention above. State and local community-support organizations, whether Parkinson's-focused or not, may also have information or ability to help you find or start what you're looking for.

You might also try contacting nearby physical therapists. Many exercise-focused groups for people with Parkinson's and other neurological conditions are led by physical therapists. Even if there's not an existing group, you might be able to start one by connecting with the right PT.

HOW CLINICAL TRIALS CAN CONNECT YOU WITH COMMUNITY

In Chapter 3, we talk about the power of giving back and how it can help you live well with Parkinson's. There's one way to give back that can make such a difference, it deserves its own spotlight as we talk about our Parkinson's community: participating in clinical research.

Below, long-time Davis Phinney Foundation board member Pete Schmidt provides an overview of the clinical trial process. Before that, let's highlight how participating in research has helped many people become better informed and better connected in their communities.

There are three main ways that taking part in research creates connections for you:

- You'll meet additional care providers and Parkinson's experts.
- You'll meet other people with Parkinson's.

- You'll become part of a global movement to advance understanding of Parkinson's, perhaps even making an impact beyond the Parkinson's community itself.

Participating in research is a personal decision, and there are several ways to do so. Research doesn't always involve drugs; there are also exercise-based trials, music-based trials, and other opportunities. Don't dismiss the idea of participating in research simply because you don't want to take an experimental drug.

If you're interested in learning more about Parkinson's, connecting with others who share that interest, and helping advance global understanding of Parkinson's, talk with a member of your care team about what trials are available in your area. If you find a trial you're interested in, talk with your team about whether it would be a good fit for you.

You can also find information about trials at **clinicaltrials.gov**, the Michael J. Fox Foundation's "Fox Trial Finder," and our website, **dpf.org**.

> **Becoming engaged in the Parkinson's community through organizations like the Davis Phinney Foundation is one of the most powerful steps you and your care partner can take to live well with Parkinson's. When you connect with others, you discover ways to better communicate about the symptoms you experience and can learn successful strategies for living well that others have adopted. When you connect and communicate, the great reward is learning you are not alone."**
>
> — GREGG BUSCH

Photo courtesy of Parkinson Canada

Can You Tell Me More about Participating in a Clinical Trial?

By Peter Schmidt, PhD

With dramatic advances in neuroscience, there has never been a time with more promising Parkinson's therapies in the clinical development pipeline. Our understanding of Parkinson's disease keeps advancing, and this knowledge is inspiring new ideas that are being tested in clinical trials.

Let's look under the hood at how clinical trials advance science. To start, let's talk about science and engineering, two ways that society makes progress.

In engineering, we have a number of tools that we know work, and we combine them to solve a problem. Think about building a bridge: we may have never crossed this river in this exact place before, but we can survey the banks, consider the properties of steel, wood, and concrete, and design a bridge that we have complete confidence will cross the gap.

Science is for when we don't know. We think we have an idea, but we want to test that idea, open to the idea that it might or might not work. Throughout human history, ideas about how the world fundamentally works have been more often wrong than right, so we need to approach science with the humility that our ideas may not solve the problem.

SCIENCE AND ENGINEERING IN PARKINSON'S RESEARCH

When we design new drug candidates for treating Parkinson's, we build on the accumulated knowledge of nearly 75 years since the Nobel Prize-winning work that identified the role of dopamine and levodopa in Parkinson's.

We now have a very good understanding of how brain cells—neurons, astrocytes, glia, and others—are involved in the development of Parkinson's. We understand the mechanisms of brain cell signaling affected by the loss of dopamine cells, a phenomenon that is the hallmark of Parkinson's. We also have some pretty good theories about how aging neurons have decreasingly effective cellular waste disposal mechanisms, resulting in the buildup of a protein called alpha-synuclein that many Parkinson's scientists focus on.

Many recent Parkinson's clinical trials target processes resulting in alpha-synuclein, but there are many other approaches being investigated as well.

For example, there are also trials looking at new ways to replace lost neurotransmitters and to smooth out the ups and downs of dopamine replacement that result in OFF times and dyskinesia. While these drugs probably won't slow the loss of neurons, they may very well help people live a better life with Parkinson's.

Here's where you come in. If you have Parkinson's, or if you are a care partner for someone with Parkinson's, the greatest impact you can have on the future of Parkinson's is by volunteering to participate in a clinical trial. (Okay, if you are very rich and can fund something amazing, then that will probably also have a big impact! But even if you donate money to organizations, you can also volunteer for a trial.)

Clinical trials are a great way to make a difference because they are designed with the hope of helping people, expanding our scientific understanding, and developing new tools for living well with—and ultimately curing—conditions like Parkinson's.

THE CLINICAL TRIAL PROCESS, STEP BY STEP

To start a clinical trial, the scientist who leads the trial—often referred to as the "principal investigator" or "PI"—has to write a proposal and convince a funder that this trial will be a success. This is true whether it is a study of exercise funded by the US National Institutes of Health (NIH) or an industry-sponsored trial of a drug. As you might imagine, the major funders, whether they are Wall Street investors or NIH reviewers, see hundreds of proposals and choose carefully. They consult other scientists and study the proposals in detail to identify the best, most promising ideas.

After securing funding, PIs have to write a proposal to their organization's board of ethics. This proposal explains what the trial is, why they are doing it, and what they are doing to protect volunteers from harm. For a new drug or device or other treatment (together we can refer to these as the "intervention"), if there is any risk of harm, the intervention will be first tested on healthy people in what is called a Phase I trial.

The safety of drugs and devices is the highest priority of regulators. You've probably heard the Hippocratic oath for doctors starts with "First, do no harm." Bleach will kill bacteria, but it is bad for you, too. Regulators figure out whether they should or should not approve an intervention by first proving it is safe, *then* proving it is effective.

Why test an intervention in healthy people? Can you really find anything about how a drug will work in a person with Parkinson's by giving the drug to healthy people? Yes! If drugs have side effects (referred to as "adverse events" when they happen in trials), they usually happen because of how the drug interacts with some aspect of your body that is not the disease the drug targets. Levodopa causes severe nausea in people, but not because of how it treats Parkinson's. It causes nausea because of how the drug interacts with a different part of your body. Carbidopa, which is mixed with levodopa in the pill called Sinemet, mostly prevents the nausea effect.

Phase I trials are typically run in a hospital-like environment, with participants staying at the trial site until the treatment is done and—for a drug trial—until the drug has been cleared by the participant's metabolism. Phase I trials are very serious. Scientists and regulators want to know for sure that the drug doesn't harm participants.

After a Phase I trial, an intervention will be evaluated in a Phase II trial. This is where we try to figure out how much of a drug is the right amount to use to treat a person living with the condition(s) being studied. It is technically also part of the safety testing, but in Phase II, we also want to see signs that an intervention is effective at treating disease. Phase II trials are usually done in regular clinics where the participants who are seen by a neurologist (in the case of Parkinson's trials) and then go through an array of evaluations and tests.

If everything works out in the Phase II trial, and we know the right dose to test and the effect we expect it to have, then treatments will reach the final level: Phase III. In the US, the Food and Drug Administration (FDA) requires that most drugs be tested in two or more Phase III trials, and these trials will be large and will enroll many participants. In Phase III, it is required by regulators that an intervention makes participants "feel better," which can be tested many ways. A Phase III trial ultimately is not successful unless the people who get the trial intervention report that they are doing at least a little bit better than the people who receive the comparison intervention.

This is why your participation is so crucial: the FDA will not approve a new treatment because a biologist says, "Look at this laboratory result," or "Let me show you these scans." There has to be engagement of the trial participants, who need to answer a battery of questions that are analyzed by statisticians for signs that most trial participants who received the trial intervention reported an improvement versus those who didn't get the trial intervention.

This brings us to a key part of clinical trials: the placebo. A placebo may be a sugar pill that looks just like the treatment being investigated, or it may be some other treatment. I worked on a vaccine trial where we were developing an intra-nasal vaccine. All the participants got both a spray in their noses and a shot in the arm. Half the participants got the vaccine nasal spray and a shot of water, and half got a water nasal spray and a shot of vaccine. Making sure that everyone involved doesn't know who got what is really important in clinical trials. We call it "the blind." We must maintain the blind! It can be tough wondering what you received when you participate in a trial, but in most trials, it is important that you don't know. Many trials offer what is called an "open label extension," meaning that all participants can eventually receive the treatment if there are signs it is working.

There are other kinds of trials, too. University clinics often conduct clinical research on care models, exercise programs, and other things. Doing clinical research is how we learn if a good idea actually helps people. Participating in any trial is important.

THE BENEFITS OF PARTICIPATING IN A CLINICAL TRIAL

So what are the benefits of participating in trials? Trial participants usually receive more dedicated attention from their doctor. Study visits are usually longer than regular clinic visits, and more people on the clinical team will spend more time evaluating how you are doing. I was speaking once with the chief scientist at a government health agency, and he said that if he got sick, he would want to be in a trial. He said that doctors are highly motivated to spend the extra time to deliver the best care to their trial participants. I agree with this. When I get sick, I seek treatment from a doctor who does clinical trials.

If the drug in your trial works, you will be among the first to receive its benefits. However, I don't encourage people to try to guess what will work and what won't. Your neurologist has an ethical obligation to only run trials where he or she thinks it has at least an even chance of benefitting you. If there is any risk of harm, the trial has to be conducted in a special way, and the PI is legally required to explain that risk to you. If you have any questions, ask.

When I read scientific papers describing clinical trials in Parkinson's, the graphs of the patient status always start with an improvement—in both the intervention and placebo groups—because participants are getting a lot of attention from a top neurologist who is focused on providing the best care.

Even trials where the intervention doesn't provide a better result than the placebo are important to advance our knowledge. When a drug company asks me to help

them design a trial, I have a number of observational and failed trials that I look back on to think about what they tell me about how different aspects of trials worked. You can often see the impact of a trial that you participated in by checking **ClinicalTrials.gov** after the trial ends. The PI will update the record after the trial with the results and scientific papers that were published.

One of the things that I love about the Davis Phinney Foundation is our focus on empowering people to take charge of their Parkinson's. As we say, "every victory counts," and volunteering to participate in research is one great victory you can achieve for yourself and for everyone living with Parkinson's.

Peter Schmidt, PhD, is a scientist-executive focused on managing clinical research projects and programs. Dr. Schmidt is active in research, specializing in the intersection between mathematics and medicine. He serves as an advisor to several government, industry, and foundation initiatives and has recent or current advisory engagements in wearable sensors, telemedicine, remote monitoring, and clinical trial design. From 2009 through 2018, Dr. Schmidt served as senior vice president and chief research and clinical officer at the Parkinson's Foundation, where he oversaw research, education, and outreach initiatives. He served as principal investigator for the Parkinson's Outcomes Project (POP), designed to identify best practices in Parkinson's care, from launch through the 10,000th participant recruited. Educated at Harvard and Cornell, he completed a fellowship at New York's Hospital for Special Surgery and has held appointments in neurology, biochemistry, and public health. He also served as Vice Dean for Operations at East Carolina University's Brody School of Medicine and as ECU's Senior Associate Vice Chancellor for Medical Affairs.

SNAPSHOTS FROM THE PARKINSON'S COMMUNITY AROUND THE WORLD

There are multiple versions of this book. We published the first edition in 2010 in the United States, but we also partner with Parkinson Canada and Fight Parkinson's, an organization based in Australia, to extend the reach of this resource.

An important thing we've learned is that all around the world, people with Parkinson's do better when they are part of a community. Again and again, people tell us that the silver lining of their Parkinson's diagnosis was discovering a community they never expected but now can't imagine living without.

After you begin to share your diagnosis, you'll meet many people with personal connections to Parkinson's. Some may even be people you've known for years without awareness of their connection to Parkinson's. You'll find a world of professionals, from neurologists and nurses to nonprofit advocacy organization staff, working to support you

and help you achieve your everyday victories. And you'll meet wonderful people at the support and exercise groups we've talked about in this chapter.

Maybe most inspiring of all, around the world, the Parkinson's community thrives in the spaces people living with Parkinson's create for themselves, from bowling leagues and monthly pub meetups to hiking clubs and more. Karen Lee, president and CEO of Parkinson Canada, shares an example:

> **"The Spinning Wheels Tour beautifully demonstrates the strength of community. Co-Founders Steve Iseman, Lloyd Taylor, Mike Loughrin, and Jim Redmond cycled across Canada, raising awareness and crucial funds every step of the way. The cyclists met with local support groups, families, and neighbors, all while sharing stories and building meaningful connections. The tour is now a nationwide movement of solidarity and resilience, uplifting people living with Parkinson's and showing the true power of community."**

Connecting with community not only helps fight isolation, it exposes you to the unique wisdom others have developed while navigating the changes of life with Parkinson's. Polly Dawkins, executive director of the Davis Phinney Foundation, has seen this in action:

> **"Peer wisdom often comes not from grand gestures but from the everyday creativity and generosity of people living this experience. One person who embodies this is Jan Grimes, a Davis Phinney Foundation Ambassador who has become famous in our circles for her 'hacks': small, ingenious ways to make life with Parkinson's easier. From kitchen shortcuts to bathroom adaptations, she shares them freely and generously. What might seem like minor tips to some have been game-changing for others—we hear this all the time in online comments and other feedback we receive."**

Together, we are a force to be reckoned with. The progress we see in research and treatments and the expansion of resources for people with Parkinson's has only been possible because the community continues to demand more. Emma Collin, CEO of Fight Parkinson's, testifies to it:

> **"In 2023, Fight Parkinson's launched the Lift the Lid campaign—sharing the voices of 12 people living with Parkinson's—to challenge stigma and deepen understanding across Australia. Through storytelling, we learned from lived experience and shone a light on the real impact of Parkinson's on people's lives."**

> **When people living with Parkinson's come together to share their stories, their collective voice becomes a catalyst for change. These authentic and powerful accounts replaced misunderstanding with empathy and isolation with connection. Together, their courage raised awareness, inspired hope, and transformed how Parkinson's is seen, understood, and supported—a testament to the strength of unified community advocacy."**

Finding your people is one of the best things you can do to live well with Parkinson's. As organizational leaders, we are motivated every day by this community, and we know we could not do what we do without its power, resilience, and determination.

And remember, it doesn't matter what you do to come together. It just matters that you do.

How Can I Find Purpose and Joy, Both Within and Beyond the Parkinson's Community?

By Kat Hill

When I wake up each morning, after over a decade of living with my diagnosis, I no longer think first about Parkinson's. For me, living well means living beyond the mental filter of disease. Doing that means finding strength in myself. It also means finding inspiration beyond myself: in my loved ones, in this beautiful world, and in the community we share.

Each day, I look for the glimmers, those small things that make me smile or bring a spark of joy. Where do I find them? I have a community of people who are important to me, a loving and engaged family, friends near and far, and a trusted health care team.

I also face the day ahead with hope: I keep my focus on what I can do, I think about how I will contribute to our household, and I think about how I may be of service to others. I have built a life that allows for flexibility with symptoms and have learned to be honest with myself and others about my ability. Honesty and transparency with colleagues and friends have helped me to build realistic expectations for myself and those I work with.

Movement is an important part of living well for everyone, not just those of us with Parkinson's. I have chosen a life that gives me opportunities to stay active in the

tasks of daily living: working on our land, clearing debris, caring for Baxter (our Yorkshire terrier), and planning and making nourishing meals. On the days when physical tasks are tough, I keep a basket nearby with my floor mat and stretching aids so that I don't have to think too hard about how to keep moving.

On the more symptomatic days, I may choose to listen to podcasts or catch up on my voice-to-text communications, saving the "heavy lifting" tasks that require more energy for a less symptomatic day. I may not be able to do as much meal prep, but I can contribute by making a shopping list or planning meals for the days ahead. I try hard not to spend energy being frustrated with the symptomatic days. The energy I used to be frustrated or sad is now channeled, at least most times, into what I can do. Modulating my energy means working acceptance into a daily practice. Mindfulness, art, journaling, and a gratitude practice all help me to stay connected to this value.

Recently, my husband and I spent time thinking about how we envisioned the next season of our lives. As empty nesters with our children launched solidly into adulthood, we let ourselves fantasize and ultimately "right-size" those dreams into a next step that felt affordable and met our goals. We found a small cabin on some property we love. We're living within our means and focusing on quality connections with those we love the most.

In fact, living within our financial means has also helped me live well. Not long after my diagnosis, we realized that my lost income would significantly impact the way we were living. Over time, we consciously chose to downsize our home and our belongings. Having a smaller home and less stuff to manage has freed up a great deal of space both physically and mentally and allowed us to pursue other interests. We even were able to spend nearly two years living and traveling in a travel trailer across the US.

Our shared values of service and lifelong learning helped guide us toward life choices that continue to enrich our lives as we transition into elderhood. My husband has trained to be a volunteer firefighter and plans to earn his EMT licensure. He is active in our local fire and rescue district. Along with the many volunteer opportunities with Parkinson's organizations, I am helping with rural health initiatives at a local hospital. In these circles of service, we find joy and purpose, and I find belonging and fulfillment.

For us, this is a rich life that keeps us moving forward and living well. I believe we all can find ways, even on the very toughest days, to find the glimmers that help us to keep living well.

After receiving a diagnosis of young onset Parkinson's at 48, **Kat Hill** has learned to build a life based on gratitude and joy, not only for peace of mind, but as a fundamental building block for her existence. She ended her practice as a nurse-midwife after delivering more than 800 babies and decided to apply the best of her background and experience to help others find deeper joy in their lives. Serving as a Davis Phinney Foundation Ambassador and speaking around the world allow her to connect with the global Parkinson's community. A writer, co-host of ***The Parkinson's Podcast Unfiltered***, artist, and advocate, she co-authored her first book, ***Being Well with Chronic Illness***, in 2022. She lives in the northwest United States with her husband Ken and their excitable Yorkie, Baxter.

If I Can't *Get* Better, How Can I *Be* Better—and Live Well Today?

By Connie Carpenter Phinney

I'm a care partner. Like many of you, I knew almost nothing about Parkinson's when my husband Davis was diagnosed at age 40 in 2000. At the time, it felt like some people in the medical establishment—the diagnosing and treating doctors in our early years—were also a bit clueless. One doctor told us that with the right medicines, Davis would feel as good as he ever had--and then prescribed medicines that left him so tired, he was drowsy for the next two months and felt incapable of doing much of anything.

Back then, we had so little access to information and no resources for young onset Parkinson's. The internet was in its infancy, which meant that information was either delivered person-to-person or via a small brochure. The neurologist saw Davis for 15 minutes, prescribed medication, and told us to come back in six months. I sat in the corner listening but unable to add much to the conversation. I felt like a kindergartner. But I was already learning to make friends with the disease.

It wasn't in our nature to give up, but we did have to learn to give in to the realities of Parkinson's. At the time, it wasn't disabling, but it was omnipresent and fatiguing. We were both entrepreneurs, and Davis was consulting with many companies and traveling more than he did as a professional cyclist. He, and we, backed off and put his welfare first.

Davis and I harnessed our energy and leaned into our elite athletic backgrounds. Both of us had been Olympic-medal-winning cyclists. We were unaccustomed to defeat. Or, at least, after a setback in competition, the thing we knew how to do was work harder and find a way to be the best. What could we do with this diagnosis and the new, unwanted guest that was—is—Parkinson's?

We realized the next step was going to be work, but a different kind. If we couldn't work toward *getting* better (as in, being cured), we'd have to work toward *being* better. That's our Olympic mindset, applied to Parkinson's. We realized that meant staying active, continuing to work toward better days and, for Davis, achieving better symptom management.

In everyday life, when you wish a sick person to get better, it's usually because that person can heal and recover fully. Parkinson's offered no hope in terms of a cure. But could we—could he—find a way to *be better*? We had to think so.

In the beginning, it was hard. But soon we began building a team of medical professionals, family members and friends. We went to school by sitting with and talking to others who had Parkinson's. We learned more about our options and choices. We took some chances with our lifestyle, but kept our focus on family and our communal health.

After four tiring years, Davis felt called to be more public about and advocate for his disease. Jointly, we decided it was time to put his name on a foundation, and the Davis Phinney Foundation for Parkinson's took shape. We needed several years to refine our focus and our mission. Much of our ethos came from my mom, who had lived with another neurological condition, multiple sclerosis (MS). She had little support, and in the 1960s, the medical field did not have much to offer except to passively wait for a cure.

Waiting didn't suit Davis and me. It just isn't our mindset. The Foundation didn't (and doesn't) fund curative research. This is partly because there were other, bigger organizations doing that, but more because people living with the disease needed more information now, more hope now, and a better plan of action for living well now.

If we couldn't do *getting* better, we would do *being* better.

The mission of the Davis Phinney Foundation is simple: to help people live well today. But the challenges ahead for a person with Parkinson's and their care partner are far from simple. It's a complex—and often confounding—degenerative disease, but one where the research has confirmed that lifestyle matters.

The *Every Victory Counts* manual was created to address the complexity, but also to inspire a positive, proactive approach.

We wanted the newly diagnosed to have more support and a way to learn not only from medical professionals, but each other. We wanted everyone living with or adjacent to Parkinson's to know and understand their options, and we wanted to empower them to find science- and experience-based solutions.

None of this happens without a care team, and the key to most care teams is the primary care partner. It would take many more years before I felt called to advocate for people like me, care partners. Because Parkinson's can be so demanding, it's also isolating. Care partners needed more information and support. We need not only be part of our person's team, but to build our own supportive team as well.

I've worked tirelessly to be honest about the challenges of Parkinson's not only to people living with it, but also to their care partners, family, and friends. No part of this journey has been easy, but it has been rewarding. Why? Because we humans are hard-wired to help others. It is a key value for Davis and me, one that has given us great joy and meaning.

In serving the Parkinson's and care team communities, we've gained much for ourselves. We've welcomed numerous new, close friends into our extended circle, people we would not have met without Parkinson's. In our own family, we've raised now-adult children who are empathetic and kind, looking to be better in their own professional and personal lives. And we've grown close to medical professionals who have learned as much from us as we have from them. It's gratifying to find that most are as committed to the same goal as the Davis Phinney Foundation: to help you live well today.

No one chooses Parkinson's and, for now, there is no cure. But everyone living with Parkinson's and everyone who loves them can choose an Olympic mindset and strive for better. Find ways to try to be a little better, every day.

Keep going.

Connie Carpenter Phinney, MS, is an entrepreneur, author, artist, and lifelong athlete and is extremely passionate about her work with the Davis Phinney Foundation. Connie particularly enjoys sharing her experiences via the written word and is an eloquent and humorous public speaker. She has two adult children, Taylor and Kelsey, with her husband, Davis Phinney.

NEW ESSAYS

How Can I Live Alone Well with Parkinson's?

By Julie Fitzgerald

Singles with Parkinson's.

Singles with Parkinson's are people who don't have a care partner who lives with them. There are a lot of us. Some singles have been on their own for some time, while others have lost care partners as a result of divorce, the death of a partner, or many other life circumstances. Just when you thought life couldn't throw any more curveballs, you find yourself facing Parkinson's alone...without a safety net.

Webinars and resources designed for care partners often make me feel even more alone. I sometimes want to scream, "What about me?!" So, how do we cope and live well with Parkinson's without a care partner? I've given this a lot of thought, and I've come up with some suggestions:

Don't let the fear of what could happen in the future keep you from living your best life now. I'm a born worrier, and I can spend my whole day worrying about the what ifs. Or I can live in the moment. It's a choice. You get to make it every day.

Find a good local support group. If there isn't one in your area, start one. Spread the word through social media, your primary care provider, neurologist, or movement disorder specialist. Consider creating a meet-up group. Find a local coffee shop or restaurant where you can hold regular coffee get-togethers.

Establish a Circle of Care (COC). This circle could consist of friends or neighbors who agree to regularly check in on you. Your COC should be a blend of people with Parkinson's and people who don't have Parkinson's. A simple phone call to

check in on you is really the only commitment needed. You can see the initials of the names of friends, family, people with Parkinson's, and members of my COC in the inset photo. (There's a DP in there for Davis Phinney!) A few years ago, I carried these stones with me on a trip for an entire 120-mile pilgrimage in Sicily. I placed them on the steps of the ancient ruins of the Temple of Asclepius, seen as a birthplace of medicine and healthcare.

Use technology to your advantage. Invest in a smartwatch with a plan that has emergency SOS features and the ability to detect falls. Make use of apps that can help you keep track of your medication schedule and remind you when a dose is due. Set up smart home devices that can turn on and off lights and appliances. Have a smart doorbell installed so you can see who is at your door (or if the package you've been waiting for has just been delivered!).

Ask for help, or hire help if you are able. If housework or yard maintenance has become too much, pay someone to clean or mow. Consider a prepared meal service a couple of times a week to reduce the stress of cooking every day. Look into meal and medicine delivery, transportation, and shopping services, and don't forget, many volunteer groups offer these services for free or with lower costs.

Ensure your home is free from safety hazards. You can work with an occupational therapist to do this, or explore handouts and worksheets like the Davis Phinney Foundation's Home Safety Checklist.

If you have an extra bedroom, consider getting a roommate. I know, I know. You like living by yourself. You like your independence. You like your house a certain way, and the idea of a roommate makes you uncomfortable. But with a roommate, you have someone you can talk to instead of four walls; you can trade off meal preparation and household chores; and you may have the added benefit of rental income. If you don't personally know the potential roommate, screen applicants and do a background check. You should have a rental agreement to protect yourself and specify house rules, so there are no misunderstandings later.

Consider getting a service dog or therapy dog. Although service dogs can be costly, getting one that is trained to serve your needs is the optimal way to go. Not all animals have the temperament to be a service dog, so be sure to research service dog organizations in your area to ensure you are using a reputable organization. Ask for references. Waiting lists, prices, and training vary. You can use services like GoFundMe to help offset the cost of getting a service dog, and for

veterans, there are many organizations that offer service dogs free of charge. Costs for service dogs and their care are tax deductible.

In the United States, the Americans with Disabilities Act (ADA) protects the rights of people with disabilities to access public places, including stores, restaurants, hotels and hospitals, with their service dogs. Therapy dogs or emotional support animals are great company and provide lots of joy and comfort. However, therapy and emotional support dogs do not have the same guarantees to public access as service dogs. You can learn more about service animals at **ada.gov**.

Exercise. One of the most effective ways to live well with Parkinson's is through exercise. It's crucial! Many Medicare Advantage Plans include a free gym membership and going to the gym is a wonderful way to meet people. Walk around the block. If this is too much for you, walk to the end of your driveway and back. Start small and build up.

Don't be your own worst enemy. I've had to accept that I have some limitations, even though I am fiercely independent. Instead of climbing up a ladder and risking a fall, I will ask for help. It isn't a sign of weakness. It takes wisdom to realize you need help and courage to ask for it.

A happy, well-adjusted life requires balance. Don't let your life revolve around Parkinson's. Make Parkinson's revolve around your life. There may be activities you enjoyed in the past but now seem impossible. Think outside the box; is there a way you can still do these activities with some modifications? Explore other activities and hobbies you find interesting. Check the calendar at the local YMCA, the closest senior center, or another community recreation facility to see if there are activities or outings that appeal to you.

Above all, please, please don't sit at home, isolated. I know it's hard to take that first step outside your comfort zone, but for your mental and physical health, you've got to take the initiative. Doing so will help you live well with Parkinson's, knowing that you are not, in fact, facing it alone.

Diagnosed with young onset Parkinson's, **Julie Fitzgerald** turned her journey into a platform for advocacy, education, and empowerment. After undergoing deep brain stimulation surgery in 2013, she became a passionate voice for the Parkinson's community. As a Davis Phinney Foundation Ambassador, her advocacy work is broad and impactful, ranging from public speaking and educational outreach to legislative engagement at both the state and federal levels. Julie shares insights, encouragement and resources with newly diagnosed individuals and their caregivers. In 2019, she joined a 120-mile hike across Sicily with other Parkinson's and Alzheimer's advocates, featured in the award-winning film Pilgrimage to Enlightenment. Her mission is simple but powerful: to "pay it forward" with strength, knowledge, and hope.

Why Is It Important for Me to Stay Connected?

By Indu Subramanian, MD

In his book *Project UnLonely*, Dr. Jeremy Nobel discusses the many risk factors for loneliness. People with Parkinson's tick many of these boxes: they are often older, are "sick," may have a history of trauma, may be "minoritized" and can be at risk for being "left behind" due to the digital divide.

Social connection is a basic human need, just like food, water and shelter. In general populations, **social isolation is as bad for health as smoking a half a pack of cigarettes a day or being obese.** These issues can be very important for caregivers as well. We all need social connection.

THE SCIENCE OF LONELINESS AND PARKINSON'S

Lonely people are at higher risk of getting Parkinson's disease and dementia. Before the COVID-19 pandemic, Dr. Laurie Mischley, Dr. Josh Farahnik, and I performed a study looking at a large cohort of people with Parkinson's. The MVP study was designed to identify modifiable variables associated with the rate of patient-reported Parkinson's severity and progression. For this analysis, 1,527 participants with Parkinson's were available.

Individuals who responded "true" to the statement "I am lonely" reported approximately 55 percent greater symptom severity over time. The better the quality of life score, the more likely the participant was to say that they had a lot of friends or that they were partnered or married. The worse the quality of life score, the more likely they were to report being lonely.

We found that the negative effects of being lonely for people with Parkinson's were comparable in impact to the positive effects of exercising 7 days a week for 30 minutes per day. Lonely people with Parkinson's reported greater symptom severity for all 33 symptoms measured. Not unexpectedly, the greatest discrepancies between lonely and non-lonely individuals were found with social withdrawal/loss of interest, motivation/ initiative, depression, and anxiety. This data was published in *npj Parkinson's Disease* in 2020.

MAKING SURE YOU'RE CONNECTED

Loneliness can be screened with several scales. Here are three questions you can ask yourself:

- How often do you feel that you lack companionship?
- How often do you feel left out?
- How often do you feel isolated from others?

Researchers have identified three dimensions of loneliness.

- Intimate, or emotional, loneliness is the yearning for a close confidante or emotional partner.
- Relational, or social, loneliness is the longing for close friendships and social companionship.
- Collective loneliness is the need for a network or community of people who share one's sense of purpose and interests.

Loneliness can be felt if any one of these dimensions is not satisfied, so, for example, it is possible to be happily married and still feel lonely.

Health care providers need to be proactive and vigilant about these spheres of loneliness so they can seek and help treat patients who are at risk of experiencing the negative effects of being lonely in any of these unmet arenas of social contact. We all need someone to confide in or a group of people with a like purpose to which we belong. Belonging to a Parkinson's support group can be helpful in this regard.

Social prescribing is a new concept in which clinicians recommend or prescribe resources or activities in the community to help a patient develop healthy social connections. The National Health Service in the United Kingdom has implemented a "social prescribing" strategy where a health care provider can identify a person at risk for loneliness and refer them to a "link worker" in the community. This link worker helps identify social connections in that person's community such as group exercise classes, art-based therapies, volunteer opportunities, and community activities such as gardening, cooking and yoga classes.

Here are six ideas to keep in mind about remaining social and avoiding isolation:

1. **Be intentional about cultivating the relationships you already have.** Working on our existing friendships and relationships may enhance quality of life. When we address loneliness, we should consider the quality of the relationships, and not the quantity of the relationships.

2. **Consider making social connections at the same time as getting out in nature, getting sun exposure, getting exercise, or nurturing mindfulness.** Can you combine an activity that gives you exercise, sun exposure, nature, and social connection, like hiking with a friend in a park?
3. **Think about what brings you comfort.** Religious groups such as church groups—or meditation groups—can also be part of the prescription. Or this might entail connecting with a peer who has Parkinson's.
4. **Think about what brings you purpose and meaning.** Connecting to a group in your community that brings you purpose and meaning can be part of the medicine.
5. **Who is your biggest cheerleader? Your most important confidante?** Identify someone in your life who you can be honest with, who can advocate for you, and who can help motivate you to stay connected.
6. **Who else is disconnected, and can you connect with them?** Sometimes volunteering and helping people are less fortunate than you can be very impactful.

Indu Subramanian, MD, received her medical degree from the University of Toronto. She completed her neurology residency and movement disorders fellowship training at the University of California, Los Angeles. Dr. Subramanian stayed on at UCLA and is now a clinical professor of neurology. She established the movement disorder clinic at the West Los Angeles US Veterans Administration Medical Center and became the director of the VA's Southwest PADRECC (Parkinson Disease Research, Education, and Clinical Care) Center of Excellence. She is designing a yoga teacher training program for instructors interested in working with people with Parkinson's. Dr. Subramanian recently became board certified in integrative medicine and is passionate about palliative care. She hosts a virtual Parkinson's support group with world experts and co-edits a blog for people with Parkinson's.

How Can I Preserve and Enjoy Intimacy?

By Kelly Rees, PhD

There are many ways Parkinson's can change the intimacy in your relationships. Recognizing this early and talking about it openly can help you maintain connection despite the uninvited intruder that is Parkinson's. With the right support, intimacy in your life can take on new forms that are just as fulfilling as those that Parkinson's disrupts. You might even find that intimacy in your life actually improves.

WHAT IS INTIMACY?

Intimacy is the relationship you have with yourself and the connection between you and everyone else. Intimacy doesn't have to be sexual, and it doesn't require you to be in a stable, traditional relationship.

You can have intimacy as a solo person or in a non-traditional relationship. Intimacy happens when you are really accepted for who you are—and when you allow another person to know the real you. It's about presence, trust, and vulnerability.

THE IMPORTANCE OF COMMUNICATION

Communication is vital to any relationship. There are many ways of communicating, some of which may be changed or lost to Parkinson's. Feelings can shape our thoughts and direct our behavior. That's why it is so important to express them. Sharing feelings—even difficult ones—can aid intimate connection. Unspoken feelings are felt as distance, separation, or the feeling of "waiting for the other shoe to drop." Sharing gratitude and love can make life sweeter and hardships more manageable.

INVITING VULNERABLE SHARING

Make sharing vulnerable thoughts and feelings a regular part of your life. Ironically it might feel risky to do this with the person or people closest to you. Ease your way into it. Practicing with your therapist can help you express your feelings to others, and to listen to them with curiosity. Feelings aren't right or wrong, although we prefer some feelings over others. Also, feelings change like the weather. Notice them, express them, and let them go.

Unexpressed feelings can create a feedback loop. Here's an example: I want to kiss my partner but I'm worried I may drool, so I don't kiss them and then feel inadequate as a partner. I am ashamed about feeling inadequate, and the shame makes me feel even more inadequate. If I don't tell my partner what's happening inside me, I simply seem distant and uncomfortable. They have no idea that I am considering closeness but stopping myself.

TOUCH AND CONNECTION

Functional touch is touch that provides necessary care, which may be from a medical practitioner, a member of your care team, or your partner. This type of touch is necessary but not emotionally nourishing. Affectionate touch can be intimate because it provides emotional connection. It isn't necessary from a medical perspective, but it contributes a lot to well-being.

It may look like cuddling, stroking hair, hugging, holding hands, or rubbing a back. The person with Parkinson's can give this type of touch too. If you are self-conscious about what your body is doing when you touch, try mentioning it and touching anyway. You may be more bothered by your symptoms than anyone else. You may need to make adjustments for touch to be satisfying for all parties.

SEXUALITY AND SEXUAL EXPRESSION

For everyone who lives in a body, sex will change over time: what you want, what you do, how it feels. As your body, heart, and mind change over time, your sexual expression will change too. If you have relied on facial expressions and body language to communicate your interest or disinterest, you may need to learn new methods of expressing yourself. A sex therapist is skilled at conversations around sex and sexual expression in ways most therapists are not. They can help you discover and communicate what is possible and pleasurable for your changing body.

FOCUS ON WHAT FEELS GOOD

When it comes to sex, the best way to manage your changing body and abilities is to change your focus. Instead of focusing on a particular activity, focus on pleasure. Does it feel good? What used to be really fun may not feel good anymore.

Speak with your care team about support for sexual experiences. You may have issues with getting or maintaining an erection, with feeling clumsy or muscle cramping, or with lubricating. Many medications impact sexual functioning, and sometimes there are alternative medications that may work better for you. Talk with a sex therapist to get help with feelings of awkwardness, self-judgment,

and help with finding body positions, as well as supports like cushions, vaginal moisturizers and lubricants, vibrators or other sexual tools that can assist in finding that orgasm, if that is part of what you're seeking.

If I'm focused on an activity and it's no longer possible, I might avoid it and anything that reminds me of it, because I will feel like a failure and pursuing it will produce shame. I might even avoid non-sexual touch because it reminds me of what I can't do anymore. This then leads to more isolation.

You may not have the emotional energy for thinking about sex. Or you might want to do everything you can while you still are able. You may worry about hurting your partner accidentally. It may feel wrong to think about the person with Parkinson's as a sexual person. You may miss sex terribly and feel resentment at the lack of sex. Don't assume you know what anyone besides you is thinking, feeling, or wanting. Ask. Keep asking.

Note: Some people who have used a dopamine agonist can have a reaction to the medication that results in over-interest in sex, porn, gambling, or other problematic things. If you think this might be you, talk with your doctor about it immediately. See Chapter 8 for more information about impulse control disorders.

Kelly Rees, PhD, has been an intimacy and sexuality coach since 2008 and completed her PhD in human sexuality in 2018. She is a board-certified sexologist who works with many populations, such as those in recovery from drug/alcohol addiction, to provide therapy responsive to their specific issues around sex and relationships. Dr. Rees focuses on intimate relationships, sexual expression, disparate desire, shifting intimacy, alternative relating styles, and polyamory. This often includes performance issues, the impact of aging and menopause, dealing with grief, and jealousy. Clients range in age from their mid-20s to their mid-90s. Dr. Rees aims to engage the mind and heart while centering on the body and believes pleasure is important and a great way to learn!

What Is Apathy, and How Do I Manage It?

By Brad McDaniels, PhD

Apathy in Parkinson's isn't laziness or a character flaw. It's a brain-based symptom that makes it harder to get started, even on things you care about. The goal isn't to "power through," but to make smart adjustments so action becomes easier and more rewarding.

STRATEGIES FOR MANAGING APATHY

The good news is that small, targeted changes can help you get moving again and feel more like yourself.

Medications/Sleep

If your dopamine medications aren't timed well, motivation can dip. Poor or fragmented sleep can cause this as well. Bring a simple log of "stuck times" (e.g., "hard to start anything from 2–4 pm") to your movement disorder specialist. Ask about levodopa timing, add-on options, side effects like daytime sleepiness, and whether adjustments might help. Prioritize a steady sleep/wake schedule and treat sleep problems; better sleep often means better follow-through.

Small Steps

Plans that live only in your head are easy to ignore. Write down very small, time-stamped steps and put them somewhere you'll see them:

- 10:00–10:10 — Water the plants
- 10:15–10:25 — Walk to the mailbox
- 10:30 — Text Pat, "Did the mailbox walk"

This is called "behavioral activation." A therapist, friend, or care partner can help you map a realistic weekly plan and provide quick check-ins, so momentum builds.

Move Together

Activity fights apathy by giving you structure, energy, and quick wins. Options include brisk walking, cycling, boxing, dance, tai chi, or Parkinson's-specific classes. If possible, enroll ahead of time, because paying or registering increases follow-through. If you're new to exercise, start with 5–10 minutes and build slowly.

Social Routine

Apathy grows in isolation. Choose one regular, low-effort social plan each week—ideally tied to an activity (e.g., "coffee after Tuesday exercise class"). Local and

virtual Parkinson's groups make it easier because people notice when you're not there, and gentle accountability helps.

Simplify Choices

Make the next step the easiest step:

- Lay out clothes the night before.
- Keep walking shoes by the door.
- Leave the guitar on its stand, not in the case.
- Use phone alarms, a timer pillbox, or a fridge checklist.

These small "environmental tweaks" offload initiation from your brain to your surroundings.

Values Alignment

Ask, "What small action today moves me toward the person I want to be?" Tie actions to values: "I'll walk ten minutes to stay strong enough to play with my grandchild." Mindfulness can help you bring attention back to the task at hand and soften the urge to avoid doing it.

Mood Check

Depression, anxiety, and demoralization often sap initiative. If you notice low mood, worry, or hopelessness, ask about therapy and/or medication options. While no pill "cures" apathy, treating these companions can make motivation more reachable, and optimizing your Parkinson's medication often helps too.

Gentle Nudges

Global advice ("you should exercise more") rarely helps, but collaborative offers do ("at 2 pm, let's walk to the corner"). Quick check-ins by text or phone, especially when tied to your written plan, add just enough nudge without nagging.

Celebrate Wins

Success fuels motivation. Begin with short wins, track them on a visible calendar, and celebrate every completion (a check mark, sticker, or text to a friend). If a plan fails, adjust the step, don't abandon the goal.

Team Support

If apathy persists, seek professional guidance (neuropsychology, psychiatry, occupational/physical therapy, counseling). A brief team review can reset the plan, tailor supports, and restore momentum.

FINAL ENCOURAGEMENT

You don't need to feel motivated before you act. Motivation often follows the tiniest action. Choose one small step today, schedule it, tell someone, and check it off. Then do it again tomorrow. Over time, those small wins add up to meaningful change.

Brad McDaniels, PhD, is an assistant professor and program coordinator for the Rehabilitation Studies program in the Department of Rehabilitation and Health Services at the University of North Texas. Brad earned his PhD from the University of Kentucky and completed a post-doctoral research fellowship in the Department of Physical Medicine and Rehabilitation in the School of Medicine at Virginia Commonwealth University, focusing exclusively on Parkinson's. Brad is currently involved in research focusing on meaning in life, loneliness, demoralization, stigma, and other non-motor issues of Parkinson's.

Navigating the Next Steps in Parkinson's Therapy

By Christina Swan, MD, PhD

As Parkinson's advances, maintaining smooth motor control often comes at the cost of an ever-increasing pill burden. The restoration of dopamine signaling in the brain—the goal of oral therapy—becomes more complex to achieve over time as additional dopamine-producing brain cells are lost. The brain requires higher doses of levodopa to control symptoms as its ability to store levodopa diminishes. Higher levodopa doses come with increased risk of dyskinesia—uncontrollable wiggling movements—and more precipitous sensations of the medication wearing off. These swings between too much and too little movement are called *motor fluctuations*.

Even with strict dose timing and addition of adjunctive medications to prolong the benefit of a single dose, the amount of time per day with good symptom control (ON time) shrinks. Shrinking ON time and burdensome motor fluctuations can make people feel as though they are losing control to the disease. Several varieties of advanced therapies are now available to improve ON time, motor fluctuations, and quality of life. While choosing among these options can seem overwhelming, there are some key factors to consider that can help you and your movement disorder specialist select the most appropriate next path in your therapy journey.

The most important step in choosing an advanced therapy is identifying the symptoms you hope the therapy will improve. There are several reasons why people seek an advanced therapy. The most common reasons are to increase ON time, smooth motor fluctuations, reduce dyskinesia, and reduce medication burden. However, there is a subset of people with disabling tremor that does not respond well to escalating doses of levodopa. Another subset of people has intolerable side effects, such as severe nausea, dizziness, and fatigue, at very low doses of levodopa with insufficient symptom control. These people would not benefit from a levodopa-based advanced therapy.

It is also important to understand the limitations of current therapies in treating certain Parkinson's disease symptoms. Even advanced therapies struggle to improve balance and gait freezing, especially if they are not responsive to levodopa. Furthermore, no current commercially available therapies slow, stop, or reverse disease progression. Understanding your goals for an advanced therapy will help your specialist refine your options.

The next points to consider are how invasive and how much daily management of an advanced therapy you and your care partner would find acceptable. The currently available advanced therapies can be grouped into three categories with increasing invasiveness of delivery: oral, subcutaneous infusions, and surgical therapies.

Oral therapies include combination immediate-release and extended-release carbidopa-levodopa formulations. These medications can provide a more sustained release of levodopa into the bloodstream, resulting in decreased dosing frequency and more consistent ON time. More stable blood levodopa levels may also improve dyskinesia, which can occur at the peak of a dose or with wearing off. These medications will treat only levodopa-responsive symptoms and have side effects similar to levodopa. Dosing requirements and frequency would increase with disease progression.

Available subcutaneous infusion therapies include foscarbidopa-foslevodopa and apomorphine pumps. Foscarbidopa-foslevodopa is converted in the body to carbidopa-levodopa, and apomorphine is a dopamine agonist.

Both therapies utilize small, self-injected cannulas (very thin tubes) connected to a pump worn on the body to deliver medication underneath the skin continuously for direct absorption into the bloodstream. The foscarbidopa-foslevodopa infusion therapy pump can be worn as a 24-hour therapy and directly replaces all oral levodopa and levodopa extenders. The apomorphine pump can be worn as a 16-hour therapy, and its use also can simplify medication regimens. By providing continuous drug delivery, these pumps can improve ON time and decrease OFF time. Similarly to the extended-release oral formulations, by holding drug levels steady, dyskinesia can improve. Though minimally invasive, these therapies do require daily maintenance, including loading medication into the pump and/or injecting a new cannula site. Good hygiene at the infusion site is critical to decrease the risk of local skin infection. Though many patients can manage these tasks independently, others will need the assistance of a care partner. As these pumps are newly approved, the average duration of benefit is unknown.

Deep brain stimulation (DBS) and focused ultrasound (FUS) are surgical options for those who continue to have motor fluctuations and/or disabling tremor despite medication adjustments.

DBS involves the placement of small electrodes into the brain and a battery in the chest to send electrical pulses that improve symptoms of tremor, stiffness, and slowness. The electricity is adjustable to address symptom progression over time. DBS can significantly improve ON time and dyskinesia and lead to medication reduction. Though the most invasive, it requires periodic, but not daily, maintenance and can provide many years of symptom benefit.

FUS involves use of high-intensity ultrasound waves to burn a small hole in the brain. It does not require skin incisions, skull drilling, or maintenance. It is now approved for use in brain areas that treat medication-refractory tremor or motor fluctuations and dyskinesia. Unlike DBS, it is not adjustable; the lesion cannot be expanded without damaging neighboring brain areas that control balance, speech, and/or strength. Given the newness of this procedure, the average duration of benefit is still unknown; symptoms can recur over time. For older people with other medical conditions for whom DBS surgery would not be a safe option, FUS can be a good strategy.

A final point to consider is that these therapies can be pursued sequentially. Patients with levodopa-responsive symptoms struggling with motor fluctuations and dosing complexity could start with extended-release oral medications. If the oral options do not provide enough consistency, a subcutaneous pump could be tried. If symptoms remain sub-optimally treated, surgical options can provide durable improvements. Some patients choose this escalating approach. Others choose a more invasive but long-lasting therapy from the start, noting that those with medication-refractory tremor or medication-intolerance are more limited in effective advanced options. Start by having a conversation with your specialist. Your specialist can help you decide which of these treatments—alone or in combination—may best suit your symptoms, lifestyle, and goals.

Consider this Therapy for:	Motor Fluctuations (ON-OFF)	Dyskinesia	Medication Refractory Tremor	Medication Intolerance
Extended-Release Carbidopa-Levodopa	✔	✔	✖	✖
Foscarbidopa-foslevodopa Infusion	✔	✔	✖	✖
Apomorphine Infusion	✔	✔	✖	✖
Focused Ultrasound	✔	✔	✔	✔
Deep Brain Stimulation	✔	✔	✔	✔

✔ = improves, ✖ = does not improve

Christina Swan, MD, PhD, is a movement disorders specialist who provides clinical care at Rush University's Parkinson's Disease and Movement Disorders Center. Dr. Swan completed her MD and PhD in biomedical engineering at Duke University, a neurology residency at University of Pennsylvania, and her movement disorder fellowship at Rush University. She is currently an assistant professor of neurological sciences and the fellowship director of the Movement Disorders Fellowship Program. Her clinical focus is on managing advanced therapies, including infusion pumps, focused ultrasound, and deep brain stimulation.

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