



2022

— PARKINSON'S DISEASE AND — THE BLACK COMMUNITY:

HOW TO LIVE BETTER



Introduction

There are nearly one million people in the U.S. living with Parkinson's disease (PD) and that number is expected to rise.

Although efforts are underway to learn more, the full impact of Parkinson's on the Black community is unknown because of their historical underrepresentation in research and in the healthcare system overall. To date, research shows that African Americans are diagnosed later in the disease, and once diagnosed are less likely to receive care from PD medical professionals and specialists. In addition, they are also less likely to receive recommendations and referrals for treatment and advanced therapies as compared to white people with PD.

[BlackDoctor.org](https://www.blackdoctor.org) created this book in partnership with the [Parkinson's Foundation](https://www.parkinsons.org) to ensure that Black¹ people living with Parkinson's are aware of the resources and options for care that specifically consider their unique experiences and needs. The Black community may face additional challenges managing this disease including awareness of symptoms associated with Parkinson's disease and the health and economic inequities that present barriers to accessing quality care. These barriers can negatively influence health outcomes and quality of life for people with Parkinson's and their caregivers. However, initiatives are underway to improve this by conducting more targeted and inclusive research, studying health disparities, and promoting the awareness and disclosure of symptoms, so that we can more accurately diagnose PD and improve outcomes in the Black community.

This e-book is for anyone affected by Parkinson's disease: those concerned about [early symptoms](#), those newly diagnosed, those living with the disease, and those who help care for a loved one. In this book, you will find an overview of PD - its causes, symptoms, and treatments - as well as advice for navigating the PD journey and steps to take today to live your best life. Each chapter also provides links to articles, videos, webpages, and other resources to help you or your loved one with Parkinson's.

The book is designed to be a resource guide as you take control of your PD journey, so that you feel empowered to talk to your doctor and find the care that you deserve to live well with the disease. With the help of PD professionals and the support of your network, you can slow the progression of your Parkinson's symptoms and enjoy a better quality of life. To find more resources and support, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) to speak with a Helpline specialist or visit [Parkinson.org](https://www.parkinsons.org).

¹In this e-book, the term Black is inclusive of all people within the Black community, including but not limited to Africans, African Americans, Afro-Latinos, and Afro-Caribbean people.

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Chapter 1

What is Parkinson's Disease?

What is Parkinson's Disease?

Parkinson's disease (PD) is a progressive, neurological disorder that occurs when cells in the brain that make dopamine start to die. Dopamine is the chemical that sends messages to the part of the brain that controls movement and coordination. Less dopamine in the brain results in various symptoms, which progress differently for everyone.

People with Parkinson's disease can experience movement (or motor) symptoms, and non-movement (or non-motor) symptoms. Symptoms related to movement can include tremors, slowness of movement, freezing (the temporary, involuntary inability to move) and problems with balance. Non-movement symptoms can include depression, anxiety, low blood pressure, constipation, and sleep disorders. Symptoms of PD are commonly misinterpreted as normal signs of aging and for years may go unreported to a person's healthcare provider. With early detection, treatment, and expert care, many people live longer, productive lives with Parkinson's. You can learn more about indicators of PD in [Chapter 2 - Recognizing Early Signs of Parkinson's Disease](#).

The cause(s) of PD remains largely unknown and there is no cure, yet. To learn more, refer to [Chapter 3 - The Causes of Parkinson's Disease](#). Many symptoms of PD can be treated or managed, and researchers are making advances in understanding the disease, its causes and new treatment options. To make life better for people with Parkinson's, the [Parkinson's Foundation](#), a national PD organization, funds research and provides free educational materials to those impacted by the disease.

How is Parkinson's Disease Diagnosed?

There is no specific test to [diagnose Parkinson's](#). A diagnosis of PD is based on many factors including an individual's medical history, symptom history (e.g., tremors, loss of smell, reduced voice volume), neurological examination, and response to medication. Early diagnosis can help lead to earlier treatment and better quality of life.

How Common is Parkinson's Disease?

- Nearly [one million people](#) in the U.S. are living with PD and this number is expected to rise to 1.2 million by 2030.
- An estimated 60,000 Americans are newly diagnosed with PD every year.
- More than 10 million people worldwide are living with PD.
- We do not have an accurate estimate of the number of African Americans living with PD in the U.S. Many studies find that African Americans are less likely to be diagnosed with PD than whites due to a number of factors including underrepresentation in research and in the healthcare system overall. Data also suggests that African Americans with PD are, on average, diagnosed four years later and at a more advanced disease stage.
- We are learning more by conducting more targeted and inclusive research, studying health disparities, and promoting the awareness and disclosure of symptoms, so that we can more accurately diagnose PD and improve health outcomes in the Black community.

Who Does Parkinson's Disease Affect?

- PD typically affects older adults. Most people are diagnosed in their 60s.
- Young-Onset Parkinson's disease (YOPD) occurs in people younger than 50 and accounts for about 4% of people living with PD. Although symptoms are similar, people with YOPD often face different financial, family, and employment concerns.
- On average, men are 1.5 times more likely to have PD than women. This is not the case for Black men and women, who are at similar risk for PD.
- There are approximately [110,000 veterans with PD](#) who are seen through the Veterans Health Administration.

Learn More About Living Well with PD

The first step to living well with Parkinson's is to understand the disease and its progression.

- The book [Parkinson's Disease: Frequently Asked Questions](#) highlights the most frequently asked questions the Parkinson's Foundation receives through its Helpline.
- In the video [What is Parkinson's Disease?](#) James Beck, PhD, Parkinson's Foundation Chief Scientific Officer, defines Parkinson's, describes movement and non-movement symptoms and explains the importance of exercise for people with Parkinson's.
- The book [Managing Parkinson's Mid-Stride: A Treatment Guide to Parkinson's](#) is for people who are having more difficulty managing Parkinson's, and includes information about how to treat and cope with fluctuating symptoms.

To find more resources, see [Chapter 12](#) - *Parkinson's Disease Resources*.

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit Parkinson.org.



Chapter 2

Recognizing Early Signs of Parkinson's Disease

Recognizing Parkinson's Disease

It can be hard to tell if you or a loved one has Parkinson's disease (PD). The Parkinson's Foundation recognizes [10 early signs](#), listed below, that you might have the disease. No single one of these signs means you should worry, but if you have more than a few, consider making an appointment soon to talk to your doctor.

Symptoms of PD are commonly misinterpreted as normal signs of aging and often go unreported to a person's healthcare provider. Additionally, data shows that people in the Black community are less likely to receive a timely PD diagnosis, which can result in increased health risks and poorer health outcomes. Early diagnosis can help lead to earlier treatment and better quality of life.

[Talk to your doctor](#) if you are concerned about Parkinson's or simply have questions. With early detection, treatment and expert care, many people live longer, productive lives with Parkinson's. The sooner a person is diagnosed, the sooner that person can build their expert care team and tailor an individual treatment plan.

10 Early Signs of Parkinson's Disease

1. **Tremor:** A [tremor](#) while at rest is a common early sign of PD. It may start as a slight shaking or tremor in your finger, thumb, hand, or chin.
2. **Small Handwriting:** You may notice the way you write words on a page has changed, such as letter sizes are smaller and the words are crowded together. This change in handwriting is called [micrographia](#).
3. **Loss of Smell:** No longer being able to [smell](#) certain foods, like bananas, dill pickles or licorice.
4. **Trouble Sleeping:** Sudden movements during [sleep](#), like thrashing around or acting out dreams. Sometimes, your spouse or partner will notice or will begin sleeping in another bed.
5. **Trouble Moving or Walking:** [Stiffness](#) in your body, arms or legs that does not go away as you move. You may notice that your arms don't swing like they used to when you walk and some people say their feet seem "stuck to the floor."
6. **Constipation:** Feeling [constipated](#) and straining to move your bowels every day.
7. **A Soft or Low Voice:** A change in your [voice](#), like your speech sounding very soft or hoarse.
8. **Masked Face:** Others may have told that you have a serious, depressed or mad look on your face, even when you are not in a bad mood. This is called [facial masking](#).
9. **Dizziness or Fainting:** Feeling [dizzy or fainting](#) can be a sign of low blood pressure and can be linked to PD.
10. **Stooping or Hunching Over:** [Stooping](#), leaning or slouching when you stand.

Learn More About the Early Signs of PD

- The video [10 Early Signs of Parkinson's Disease](#) breaks down early symptoms.
- In the podcast episode [PD Across Race & Ethnicity](#), Reversa Joseph, MD, discusses outreach within the African American community and the importance of recognizing the early symptoms of PD.
- The book [Living Your Best Life: A Guide to Parkinson's Disease](#) provides tools for people with PD and their loved ones to process and cope with a diagnosis.

To find more resources, see [Chapter 12 - Parkinson's Disease Resources](#).

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](#).



Chapter 3

The Causes of Parkinson's Disease

What Causes Parkinson's Disease?

We do not know exactly what [causes](#) Parkinson's disease (PD), but scientists believe that a combination of genetic and environmental factors may be the cause. The extent to which each factor is involved varies from person to person, and researchers do not know why some people develop PD and others do not.

Regardless of if the cause is genetic or [environmental](#), every person with PD experiences a loss of dopamine in the brain, along with symptoms and a disease progression that is unique to them.

Genetics

Genetics cause about 10-15% of all Parkinson's. Put another way, 85-90% of people with PD will not have a known genetic cause. In some families, changes (known as mutations) in certain genes are passed down from generation to generation.

Genetic tests alone cannot diagnose Parkinson's disease, but a genetic test can be used to determine whether one carries specific Parkinson's gene mutations. These mutations may place a person at risk of developing PD; or, if a person already has a PD diagnosis, may help explain a potential cause of their disease.

Understanding the connection between PD and genetics can help us understand how the disease develops and ultimately how it can be treated or cured. This is why studies that link genetics to PD are essential, like the Parkinson's Foundation [PD GENERation: Mapping the Future of Parkinson's Disease study](#).

PD GENERation is a national initiative that offers genetic testing for clinically relevant Parkinson's-related genes and genetic counseling at no cost for people with a PD diagnosis. Participation can be either in-person or at-home. More participation from communities of color is needed to improve the results of these gene studies and better serve the Black community. To learn more, see [Chapter 8 - Parkinson's Disease Research and Clinical Trials: What to Know](#).

Environmental Factors

Scientists are working to better understand the broad range of environmental exposures linked to PD. Research shows that environmental risk factors include:

- Pesticides and herbicides
- Head injury
- Area of residence
- Occupation
- Exposure to metals
- Solvents and polychlorinated biphenyls (PCBs)

You can learn more about environmental risk factors and potential protective factors at the Parkinson's Foundation webpages on [Understanding Parkinson's Cause](#).

Learn More About the Causes of PD

- The video [PD GENERation: Mapping the Future of Parkinson's Disease](#) is an introduction to the national effort to offer genetic testing for people with PD and its importance in helping to understand how the disease develops, can be treated, and ultimately cured.
- In the podcast episode [Genetics and PD: What do we know so far?](#) Martha Nance, MD, talks about some of the genes related to PD that are under investigation, how they work, and what their effects are.
- The webpage [Questions and Answers about PD GENERation](#) details the study and explains how people with PD can participate in the clinical research study.

To find more resources, see [Chapter 12 - Parkinson's Disease Resources](#).

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](#).



Chapter 4

Newly Diagnosed: What to Know

Living Better with Parkinson's Begins Today

Receiving a Parkinson's disease (PD) diagnosis can feel overwhelming. This life-changing news can leave you unsure of your next step. As you begin processing your emotions, which can be wide-ranging, it's important to know that [you are not alone](#). No matter when you are diagnosed or the progression of your symptoms, you should feel empowered to take control of your PD journey and care. Taking charge of your diagnosis can be the first step to living your best life with PD.

For some, a [PD diagnosis](#) may be a relief and an explanation for previously unexplained symptoms. Others may be struggling with what the future of living with PD may look like. It is normal to experience different thoughts and feelings. Take time to understand how PD can impact you physically and emotionally.

If you have been diagnosed within the last few years, these five steps, in any order, can help you begin to live a better life with PD. Click [here](#) to learn more about each step.

1. Determine your personal goals and priorities.
2. Find someone you can talk to and stay connected.
3. Create and practice healthy habits.
4. Be active in whatever way works best for you.
5. Find a doctor who is an expert in Parkinson's disease.

Learn More About What It Means to Be Newly Diagnosed

- The [Parkinson.org/NewlyDiagnosed](https://www.parkinson.org/NewlyDiagnosed) webpage is the go-to resource for anyone who has recently received a Parkinson's diagnosis. Learn more about starting your journey, building your community, and taking charge of your diagnosis.
- The free [Newly Diagnosed Kit](#) is designed to help you live well with PD. The kit includes key resources, such as a PD fact sheet, informational postcard, and [key questions for your doctor visits](#).

To find more resources, see [Chapter 12](#) - *Parkinson's Disease Resources*.

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](https://www.parkinson.org).



Chapter 5

Understanding Movement and Non-Movement Symptoms

Parkinson's disease (PD) is often thought of as a disease that only impacts movement, but PD affects many systems in the body. Parkinson's symptoms are different from person to person and usually develop slowly over time.

Research findings are varied as to whether African Americans with PD experience different symptoms compared to other racial and ethnic groups. More participation by communities of color in research studies will help researchers and the larger community better understand how PD - and treatments - specifically impact Black people with PD. Learn more about PD research studies and participation safety in [Chapter 8 - Parkinson's Disease Research and Clinical Trials: What to Know](#).

Many people simply dismiss Parkinson's symptoms as a normal part of aging. Parkinson's symptoms are incredibly varied. If you have not been diagnosed with PD, no one single symptom means that you should worry, but if you notice several symptoms, consider [talking to your doctor](#) soon. To learn more, see [Chapter 2 - Recognizing Early Signs of Parkinson's Disease](#).

Movement Symptoms

Dopamine is a chemical in the brain that is primarily responsible for controlling movement, emotional response, and the ability to feel pleasure and pain. With Parkinson's, the cells in the brain that make dopamine start to die, and this causes increasing [problems with movement](#).

Movement (often referred to as motor) symptoms include:

- Slow movement (Bradykinesia)
- Tremor
- Rigidity and stiffness
- Trouble with balance and falls
- Cramping
- Involuntary movement (Dyskinesia)
- Freezing (the temporary, involuntary inability to move)
- Shuffling gait

Non-Movement Symptoms

People with PD also experience non-movement (often referred to as non-motor) symptoms. While family and friends may not be able to see these symptoms, it is important to realize that [non-movement symptoms](#) are common and impact a person's well-being. Depression and anxiety are the number one factors impacting the overall mental health and wellbeing of people with PD. Some symptoms, such as loss of smell, constipation, and sleep disorders can occur years before the diagnosis of PD.

Non-movement symptoms include:

- Cognitive changes or changes in the ability to think or remember
- Constipation
- Fatigue
- Lightheadedness
- Loss of sense of smell or taste
- Anxiety and/or depression (See [Chapter 10](#) for more information on mental health and PD)
- Pain
- Sleep disorders

Learn More About PD Symptoms

- The webinar [Non-Motor Symptoms: What's New?](#) focuses on the detection and effective treatment of non-movement symptoms. It includes specific recommendations on how to cope and live optimally with these non-movement symptoms.
- The webpage [Motor Fluctuations](#) explains why movement symptoms can change over time and how to manage these changes.
- In the podcast episode [Recognizing Non-Motor Symptoms in PD](#) Daniel Van Wamelen, MD, PhD, discusses non-movement symptoms and ways to address them.

To find more resources, see [Chapter 12](#) - *Parkinson's Disease Resources*.

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](#).



Chapter 6

Treatment for Parkinson's Disease

There is no standard treatment for Parkinson's disease (PD). Treatment for PD can include medications, exercise, rehabilitation therapies and surgical procedures. Treatment plans should be tailored to respond to an individual's symptoms, priorities and personal circumstances. There is currently no cure for PD; the goals of [treatment](#) are to minimize symptoms and improve overall quality of life.

As you start to think about treatment, it is also important to think about who will support you in managing the disease - your care partner. The primary care partner is often a family member or spouse. It is helpful for your care partner to accompany you to appointments and to be included in discussions about treatment options with your expert care team. Learn more about what it means to be a care partner to someone with PD in [Chapter 11](#) - *Care Partners, Spouses, and Family: Being Supported and Staying Connected*.

Expert Care Team

Building an expert care team is a critical component to finding the treatment plan that works best for you. Working with professionals who specialize in PD is important because they have a deeper understanding of the disease and the treatment options available to you.

PD specialists can help you to better manage your PD, reduce complications and allow you to enjoy a better quality, longer life. Finding your care team can seem like a daunting task, but it doesn't have to be. The Parkinson's Foundation can guide you [step by step](#) through the process. To learn more, see [Chapter 7 - The Expert Care Team](#).

Prescription Medications

Including medication in your treatment plan is a decision between you and your PD specialist. Each person with PD is evaluated to determine which medications are best for them. The choice of [medication](#) treatment depends on many factors including symptoms, response to medications, age and other existing health issues.

Surgical Treatment

As with medication, surgery for PD is not a cure. However, it can be effective in managing symptoms, including tremors, the slowness of movement (bradykinesia) and rigidity. There are two primary types of surgery for PD: [deep brain stimulation](#) (DBS) and the [Duopa pump](#). Discuss surgical treatments with your PD specialist to determine if they should be part of your treatment plan.

Exercise

For people with PD, exercise is a vital component to maintaining balance, mobility, and activities of daily living. [Exercise](#) and physical activity can improve many PD symptoms. Learn more about the importance of exercise in [Chapter 9 - Lifestyle: Health and Wellness with Parkinson's Disease](#).

Clinical Trials

[Clinical trials](#) are a type of research study used to test a new medication, surgery, or type of therapy. Participating in clinical trials provides people with PD the opportunity to receive excellent care while helping to bring more effective therapies to the market more quickly. To learn more, see [Chapter 8 - Parkinson's Disease Research and Clinical Trials: What to Know](#).

Palliative Care

Palliative care focuses on improving quality of life and providing additional support for people with a progressive illness. Palliative care is appropriate at every stage of PD, from diagnosis onward. [This approach](#) helps people plan for the future and provides guidance for what to expect. Palliative care not only addresses physical needs, but also the emotional, social, and spiritual needs of people with PD, family members, and care partners. Any healthcare provider can be trained in this approach and many palliative care teams include a social worker.

Learn More About Treatment Options for PD

- The book [Medications: A Treatment Guide to Parkinson's Disease](#) explains the types of medications available to manage PD symptoms and can be used when working with your healthcare team.
- The podcast episode [How Movement Disorders Fit into the Palliative Care Model](#) features Adriana Gonzalez, a social worker specializing in PD. Gonzalez discusses the benefits of palliative care, the ongoing relationship of the care team with the patient and family, and how this form of care can specifically address the needs of people with PD.
- The video [Surgical Options for Parkinson's Disease](#) describes surgical options that can be used to reduce Parkinson's disease symptoms in a subset of carefully selected individuals with a specific symptom or symptoms.

To find more resources, see [Chapter 12 - Parkinson's Disease Resources](#).

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](#).



Chapter 7

The Expert Care Team

Finding the Right Doctor

Managing Parkinson's disease (PD) can be challenging. A doctor who specializes in Parkinson's can help improve your health outcomes and support your journey with PD. A movement disorder specialist is a neurologist with specialized Parkinson's training who can provide advice and care throughout the course of the disease.

Most people begin discussing initial Parkinson's symptoms with their family doctor or internist, who may then refer a neurologist. From there, you can start to build out the rest of your [expert care team](#).

Finding an Expert Care Team

PD can impact your entire life. Every person has different PD symptoms, vulnerabilities, and needs. This is why your care team is so important. In the team-based approach, different types of experts work together to address your full range of symptoms and challenges.

While some people find all their specialists in one healthcare practice, in most cases, people with PD build their team. Though it may feel a bit uncomfortable for some people accustomed to having a single doctor handle everything, PD is a chronic, degenerative disease with varying symptoms at each stage requiring multiple specialists to help you live the best life possible.

Due to various factors, people with PD in the Black community may be less likely to see neurologists and other specialists, and therefore may be less likely to receive optimal treatment. However, working with professionals who specialize in PD is critical to helping you better manage your PD, reduce complications, and help you enjoy a higher quality of life. Specialists trained in PD have a deeper understanding of the disease and available treatment options.

Finding your care team can seem like a daunting task, but it doesn't have to be. The Parkinson's Foundation can help guide you [step by step](#) through the process.

Building Your Care Team

- **Movement Disorder Specialist:** neurologists who have specialized training in complex neurological conditions such as Parkinson's disease and experience in diagnosing and treating symptoms at every stage. The [Parkinson's Foundation](#) recommends that people diagnosed with PD have a neurologist, and ideally a movement disorder specialist, as part of their healthcare team.
- **Neurologist:** medical doctors who have specialized training and treat people with diseases of the spinal cord, brain, nerves, and muscles. Neurologists diagnose and treat individuals with conditions such as epilepsy, stroke, multiple sclerosis, Alzheimer's disease, and Parkinson's disease. For those without easy access to a movement disorder specialist, the Parkinson's Foundation recommends seeing a nearby general neurologist for routine PD care and, if possible, using [telehealth](#) to regularly meet with a movement disorder specialist.
- **Physical Therapist:** therapists who help people with PD maintain or regain mobility. They can develop customized exercises and provide treatment that focuses on walking, balance, posture, flexibility, and strength associated with Parkinson's.
- **Occupational Therapist:** therapists trained to provide services that support mental and physical health and wellness. They can help you modify your home or work environment, your approach to tasks, and even the tasks themselves to meet PD-related challenges. Occupational therapists can also help you find assistive devices, from a swivel seat for your car to a specialized computer mouse suited to your needs.
- **Speech-Language Pathologist:** professionals who assess and treat communication, speech, and swallowing problems. These therapists can help ease PD-related speaking and eating challenges if they arise.
- **Social Worker:** professionals who can help you and your family sort and resolve issues associated with the daily demands of Parkinson's and day-to-day life (e.g., insurance, housing, disability), offer counseling services, and also help you find support groups in your own community. Learn more about building your support network in [Chapter 10 - Mental Health and PD](#).
- **Other Care Team Members:** Many care teams also include a mental health professional (who may be your social worker) as well as a registered dietician or nutritionist. Talk to your doctor about what works best for you.

Trusted Advisor

Given Black Americans' challenging history with the medical profession, it can take time for you and your care partner to build trust with your expert care team. This is understandable, especially if your care team members do not look like you or come from your community.

You may find that your spiritual leader, a family member not in your immediate family, or a very close friend with whom you already have a trusted relationship would be a valuable addition to your care team. While this person may not be a PD expert, they can assist you in communicating with the experts, help you during medical visits, and support you by providing a safe zone to work through your thoughts and decisions along your PD journey.

Learn More About Building Your Expert Care Team

- The webpage [Building Your Care Team](#) explains who specializes in Parkinson's disease, the importance of seeing a specialist, and tips to plan ahead for an appointment.
- The podcast episode [Team Care for PD: Why It's Important](#) features Lisa Mann, a nurse and educator, discussing who should be part of a PD care team and how team members can be brought on as needed.

To find more resources, see [Chapter 12 - Parkinson's Disease Resources](#).

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](https://www.parkinson.org).



Chapter 8

Parkinson's Disease Research and Clinical Trials: What to Know

Research is vital to helping us better understand [Parkinson's disease](#) (PD). Research leads to new treatments and medications, custom prescriptions and targeted therapies better suited to communities of color and gender, a better understanding of symptoms and disease progression, and will one day lead to a cure.

The Black community is underrepresented in research. This is due to limited research recruitment efforts, financial burdens to participate, social determinants of health such as residential location, and valid feelings of mistrust towards researchers and physicians stemming from historical discriminatory and harmful research practices.

The inclusion of African Americans in PD research and clinical trials is critical because this research advances our understanding of how the disease specifically affects the Black community and our knowledge of how Black people with PD respond to PD treatments. With this information, researchers can identify and develop targeted therapies, treatments, and medications that better serve the unique clinical needs of people in the Black community living with PD. Clinical trial participation can also include completing surveys, testing an exercise regime, or following new diet guidelines. You can help yourself and others by participating.

What Is a Clinical Trial?

Clinical trials are a type of research study. When scientists develop a promising new treatment, they conduct clinical trials to make sure the treatment works. These trials could test a new medication, surgery, or type of therapy. When a clinical trial is used to study medication and medical devices, it is conducted in phases and each phase helps scientists answer different questions about the drug or device safety and efficacy.

Why Are Clinical Trials Important?

Clinical trials are the only way we can reach safe, regulated and approved breakthroughs in treatment and care. Researchers need volunteers to participate in clinical trials so that they can solve unanswered questions about PD and develop new or improved treatments. The medications that you take now are available only because of clinical trial participants.

Are Clinical Trials Safe?

Every clinical trial is reviewed by regulatory bodies such as the Food and Drug Administration, the National Institutes of Health or an institution's ethics board to protect the safety of participants. However, it is important to always consult with your doctor before deciding to participate in any clinical trial. It is understandable to have hesitations about clinical trial participation – especially given the history of harmful research conducted on Black individuals and communities. It is important to know that the researchers are required by law to clearly explain any risks and to make sure that you understand them. You have the right to ask questions and withdraw from participation at any time. Participation in studies is always voluntary.

If you are considering participating in a PD clinical trial and want up-to-date information on the trials that are currently enrolling participants, visit ClinicalTrials.gov, a database developed by the National Institutes of Health for patients and their family members.

What Are the Benefits of Participating in a Clinical Trial?

- You will have access to leading healthcare professionals, cutting-edge new treatments, and high standards of care.
- Joining a clinical trial can increase your knowledge and understanding of your disease.
- People who take part in clinical trials are contributing to science that may benefit themselves and others.
- Inclusion of African Americans in PD research and clinical trials advances our understanding of how the disease specifically affects the Black community and our knowledge of how Black people respond to PD treatments which enables development of better targeted therapies.

What Are the Risks of Participating in a Clinical Trial?

- There may be undesirable side effects to the treatment. A health professional will explain possible risks and side effects during the informed consent process.
- The treatment may not be effective.
- As in any clinical trial, participants may not receive the experimental treatment because they may be randomly assigned to the “control” group (the study group that receives a [placebo](#) or is untreated so results can be compared to determine effectiveness).

Why Is Genetic Testing Important and How Does It Relate to Clinical Trials?

[Understanding genetic differences](#) across people with Parkinson’s can help identify clues about how and why a person’s experience with the disease differs from others. Knowing your genetic status can provide a sense of empowerment and may lead to better treatment and care.

Genetic testing can help people with PD and their clinicians identify whether they carry a genetic mutation and help determine if they are eligible to enroll in certain clinical trials. Several ongoing clinical trials are already testing treatments for people who carry certain PD gene mutations (such as LRRK2 and GBA).

For people with Parkinson’s, genetic tests and counseling are not always available or covered by health insurance. To address these barriers, the Parkinson’s Foundation launched [PD GENERation: Mapping the Future of Parkinson’s Disease](#), a study that offers genetic testing and genetic counseling at no cost to people with PD in the U.S. and some Caribbean Islands.

Learn More About Clinical Trials, Genetic Testing, and their Impact on PD

- In the video [Neuro Talk: Top PD GENERation FAQ](#), James Beck, PhD, Parkinson’s Foundation Chief Scientific Officer answers questions about the national genetics study, PD GENERation, and genetic testing.
- In the podcast episode [The Skinny on Clinical Trials in PD](#), Dr. Hubert Fernandez, MD, describes the process of bringing a drug to market, why people need to participate in clinical trials, and what they can expect.
- Visit the [Advocate For Research](#) webpage to learn how people with PD and care partners make research more efficient and effective by partnering with scientists, industry, and government to represent their community’s voice.

To find more resources, see [Chapter 12 - Parkinson’s Disease Resources](#).

If you have other questions about PD or need help finding a specialist, call the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](#).



Chapter 9

Lifestyle: Health and Wellness with Parkinson's Disease

While living with [Parkinson's disease](#) (PD) can be challenging, there are many things you can do to maintain and improve your quality of life and live well with PD. The earlier a person with PD begins these health and wellness activities, the more likely they are to experience better health outcomes.

Exercise

For people with PD, [exercise](#) is medicine! Physical activity has been shown to improve many PD symptoms, from balance and mobility issues to depression, constipation, and even thinking skills. Establishing early exercise habits is an important component of overall PD management. Do something you enjoy that fits your schedule. A Parkinson's Foundation study shows that people with PD who start exercising earlier and a minimum of 2.5 hours a week, experience a slowed decline in quality of life compared to those who start later.

Diet and Nutrition

The choices you make about food impact your health and comfort. The [right foods](#) will optimize your medications, keep your bones strong, fight constipation and weight loss, and maintain general health and fitness. While there is no prescription for a PD-specific diet, to maintain overall good health most people living with PD should eat a variety of whole grains, vegetables, fruits, milk and dairy products, and protein-rich foods such as meat and beans. Remember to stay hydrated.

Dental Health

Maintaining [dental health](#) is important for people with PD. Parkinson's symptoms can complicate dental care and people living with PD can face serious consequences for oral conditions. Quickly addressing dental difficulties can help you continue to live well.

Sexual Health

Sex is a natural part of the human experience. People living with PD may face concerns about its impact on their ability to have and enjoy sex. Sexual dysfunction is common in men and women with PD. The issue often goes unaddressed as patients, spouses, and healthcare providers may not be comfortable discussing sex. Parkinson's itself may cause sexual dysfunction due to the loss of dopamine. Medications, such as anti-depressants, can also contribute to sexual dysfunction. [Sexual health](#) should be as much a part of the conversation with your healthcare team as any other health matter.

Rest and Sleep

PD creates many challenges to getting a good night's rest, both for the person with PD and the care partner. Sleep disorders can be a Parkinson's symptom or a medication side effect. Bring this issue up with your doctor, as sleep is an important component of overall health and its importance in PD cannot be overstated.

Learn More About Maintaining a Healthy Lifestyle with PD

- [PD Health @ Home](#) provides weekly online educational and wellness programs. Register for future virtual events or watch recordings of past events.
- The book [Fitness Counts: A Body Guide to Parkinson's Disease](#) contains descriptions and explanations of specific exercises that can help to maintain flexibility, strength, and aerobic conditioning.
- In the podcast episode [The Importance of Good Nutrition for People with Parkinson's](#), Bas Bloem, MD, PhD, describes how diet can help improve some of the symptoms of PD and optimize the effects of medication, and he offers tips on getting adequate nutrition.
- The book [Sleep: A Mind Guide to Parkinson's Disease](#) addresses healthy sleep, sleep changes due to aging, and sleep problems due to Parkinson's

To find more resources, see [Chapter 12](#) - *Parkinson's Disease Resources*.

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit

[Parkinson.org](#).



Chapter 10

Mental Health and Parkinson's Disease

Just as the right diet and medications are key to living well with Parkinson's disease (PD), maintaining emotional health is essential to your physical health. Mental health conditions are underdiagnosed in people with PD and, often, people with PD do not share their mental health symptoms with their providers. Whether you are newly diagnosed or have been managing your PD for years, it is normal for you and your loved ones to experience [different emotions](#). Accepting those feelings and learning how to navigate them is important.

Listen to Your Feelings

PD symptoms and treatments can affect your mood. [Depression](#) and anxiety affect up to 50% of people living with PD. [These changes](#) can also negatively impact your physical health and quality of life, but help is available. Mental health can be greatly improved with professional support and medical treatment.

People with PD in the Black community may face additional barriers to accessing mental health services. The cultural stigma associated with mental health challenges, the expectation that mental health symptoms should remain private, and the lack of providers who are culturally sensitive to the needs of African Americans could make it difficult to access appropriate mental health treatment and support. There are different types of healthcare professionals who can provide support for your mental health needs including a psychologist, psychiatrist, therapist, mental health counselor, social worker, as well as your movement disorder specialist and neurologist. For help finding a culturally sensitive doctor near you, try the [Find A Doctor](#) search tool on BlackDoctor.org.

Build a Support Network

Do not underestimate the impact of a strong support network for both you and your care partner. Choosing to disclose a PD diagnosis with your loved ones can be challenging, let alone discussing your experiences with the disease. It is normal to have hesitations about opening up. However, sharing your feelings with your family and friends can provide opportunities for connection, comfort, understanding, and support.

Consider joining activities like a prayer group at church, mosque, or other house of worship or a support group within the PD community. Support groups in your own community can provide the opportunity to talk about shared experiences with people who look like you and can help prevent feelings of isolation. Support groups can also be particularly helpful in identifying educational materials, PD specialists, and other community resources. Staying connected can relieve stress and lead to new friendships. You and your care partner are not alone.

Explore Spirituality

Focusing on the deeper meaning of your life can offer comfort. Spirituality means something different for everyone. Prayer, meditation, and talking with a faith leader are some ways that people with PD find strength, inner peace, happiness, and a deeper connection to the divine or their community.

Be Kind to Yourself

Living with a chronic disease can be overwhelming and finding the support you deserve can take time. It is normal to have feelings of sadness, frustration, or anger as you navigate your disease and the mental health care system. Remember that you are not alone, and that mental health is individual to each person. Give yourself the opportunity to try different things as you find the wellness routine that works for you.

To get started, try simplifying your daily schedule, setting short-term goals, focusing on what you can do, and asking for help where you need it. Be open and honest about what you are going through. Trust yourself to handle the challenges a PD diagnosis may bring. Reflect on past experiences and how you overcame difficulties to give yourself confidence moving forward.

Learn More About Mental Health and PD

- The book [Mood: A Mind Guide to Parkinson's Disease](#) explains what mood changes can happen in Parkinson's disease, why people with Parkinson's might experience these changes, and how to treat and cope with them.
- In the podcast episode [Mental Health in a Medical Setting](#), Kara Barton, a social worker who specializes in PD, discusses how to recognize mental distress, ways to access care, the healthcare providers who can help, and possible ways of getting care when insurance does not cover it.
- The webinar [Mental Health and Parkinson's Disease](#) focuses on the overlap of motor, cognitive, and psychiatric aspects of PD.

To find more resources, see [Chapter 12 - Parkinson's Disease Resources](#).

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](https://www.parkinson.org).



Chapter 11

Care Partners, Spouses, and Family: Being Supported and Staying Connected

The Care Partner Role

A care partner is anyone who is caring for a person living with Parkinson’s disease (PD). People with PD may have several care partners who share in the role of caregiving - spouses, children, extended family members, and friends. The responsibilities of [care partners](#) may include helping a loved one with daily activities, managing medications, and making financial decisions. Whatever your responsibilities, define the role of “caregiving” for yourself. Early in the PD journey, you may not feel like you are actually “giving” care. Similarly, your loved one may not see themselves as someone in need of care. But remember, care is not limited to physical tasks. Care can be emotional and spiritual as well as physical.

Caring for You

While your loved one’s PD diagnosis probably changed your life overnight, care partner is a role and an identity that you grow into. It does not have to erase or replace the current ways you see yourself or the existing roles you play. Research on care partners of people with PD is limited, but we do know that care partners are rarely asked what they do to take care of themselves. Remember that your needs matter too; if you do not [take care of yourself](#), you will not be able to take care of your loved one.

Whether you care for someone who is recently diagnosed with Parkinson's disease, are adapting to new challenges as the disease progresses, or have been caring for someone with PD for a long time, a strong support network is essential for your wellbeing. In the Black community, you may find it challenging to be open with your friends and family about what you are going through as a care partner. It is also normal to have hesitations about sharing these more private and personal experiences. Making sure that you are taken care of can help create a productive partnership that minimizes stress and conflict.

You and your loved one with PD [are not alone](#). Finding a network of people with whom you can share experiences provides opportunities for connections and can help prevent feelings of isolation. Consider joining activities like a prayer group at your church, mosque or other house of worship or a support group for PD care partners.

Caring as a Family

PD affects the whole family and for many, caregiving is deeply rooted in cultural values. Although there may be one primary care partner, family and friends sometimes help to provide additional support. Things like driving to medical appointments, preparing meals, and simply spending time with the person who has PD can enable the primary care partner to take a little more time to care for themselves. All [caregiving tasks](#) are important - big or small.

People who live far away are often at a loss as to how they can be helpful in ways that are both meaningful and possible. Living out of town does not mean you are not involved or do not care. There are many ways you can still help. Ask your loved one and their other care partners about what you can do to provide support. For example, calling the person with PD on a regular basis may provide a needed mental boost.

Learn More About the Care Partner Experience

- The book [Caring and Coping: A Care Partner's Guide to Parkinson's Disease](#) offers tips and tools to help prepare you for every step of the care partner journey.
- The [Care Partner Program](#) is a completely free online program made up of self-paced courses designed by and for Parkinson's care partners.

To find more resources, see [Chapter 12](#) - *Parkinson's Disease Resources*.

If you have other questions about PD or need help finding a specialist, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) or visit [Parkinson.org](#).



Chapter 12

Parkinson's Disease Resources

Managing a chronic disease can feel overwhelming, but you are not alone. With the right tools and support, you can take control of your journey with Parkinson's disease (PD). The Parkinson's Foundation is your trusted ally for information at every stage. [Parkinson.org](https://www.parkinson.org) offers an extensive collection of free articles, digital books, fact sheets, videos, webinars, podcasts and ways to connect. Use these essential Parkinson's resources to support your journey with PD.

Ways to Connect (English and Español)

- [Parkinson's Foundation Helpline](https://www.parkinson.org/helpline): To speak with a Helpline specialist, call 1-800-4PD-INFO (1-800-473-4636) or email Helpline@parkinson.org. The Helpline can also connect you with community resources.
- [PD Conversations](https://www.parkinson.org/pd-conversations) online community forum to connect with peers
- [PD Health @ Home](https://www.parkinson.org/pd-health-at-home) weekly virtual educational, health and wellness programs

For Those Concerned About Possible Symptoms

- [10 Early Signs of Parkinson's Disease](https://www.parkinson.org/10-early-signs-of-parkinsons-disease) webpage

For Help Finding a Doctor

- [Finding the Right Parkinson's Doctor](https://www.parkinson.org/finding-the-right-parkinsons-doctor) online guide
- [Resource Map](https://www.parkinson.org/resource-map) to find expert PD care near you
- [Find a Culturally Sensitive Doctor](https://www.parkinson.org/find-a-culturally-sensitive-doctor) free search tool from BlackDoctor.org

For All Stages of Parkinson's (find more at [Parkinson.org/Library](https://www.parkinson.org/Library))

- [Frequently Asked Questions](#) and [Managing Parkinson's Mid-Stride](#) books
- [Parkinson's and Medications: What's New](#) webinar
- [Exercise and Parkinson's](#) fact sheet
- [Aware in Care Hospital Safety Kit](#)
- [Walking with Parkinson's: Freezing, Balance and Falls](#) blog
- [All books from the Parkinson's Foundation](#) available on *Kindle*

For People Newly Diagnosed with Parkinson's

- [Advice and testimonials](#) video from others newly diagnosed
- [Newly Diagnosed Kit](#) with actions to get started after a diagnosis
- [Living Your Best Life with Parkinson's](#) online book

For Care Partners

- [Parkinson.org/Caregivers](#) webpage
- [Caring and Coping](#) online book
- [Top 10 Essential Caregiver Resources](#) blog
- [Care Partner Program](#): free online courses for care partners

Español

- [Recursos en Español](#) sitio web
- [Preguntas frecuentes](#) libro
- [Aware in Care Kit](#) para hospitalización

Specialty Resources

- [Social Determinants of Health](#): Centers for Disease Control resources about the many factors affecting health
- [Diversity, Equity, Inclusion \(DEI\) and PD](#): the Parkinson's Foundation's commitment to DEI
- [COVID-19 and PD](#): what you need to know about Parkinson's and COVID-19
- [Veterans and PD](#): resources and services for veterans living with PD

For the latest in Parkinson's news visit [Parkinson.org](https://www.parkinson.org) and [Parkinson.org/Subscribe](https://www.parkinson.org/Subscribe).

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