

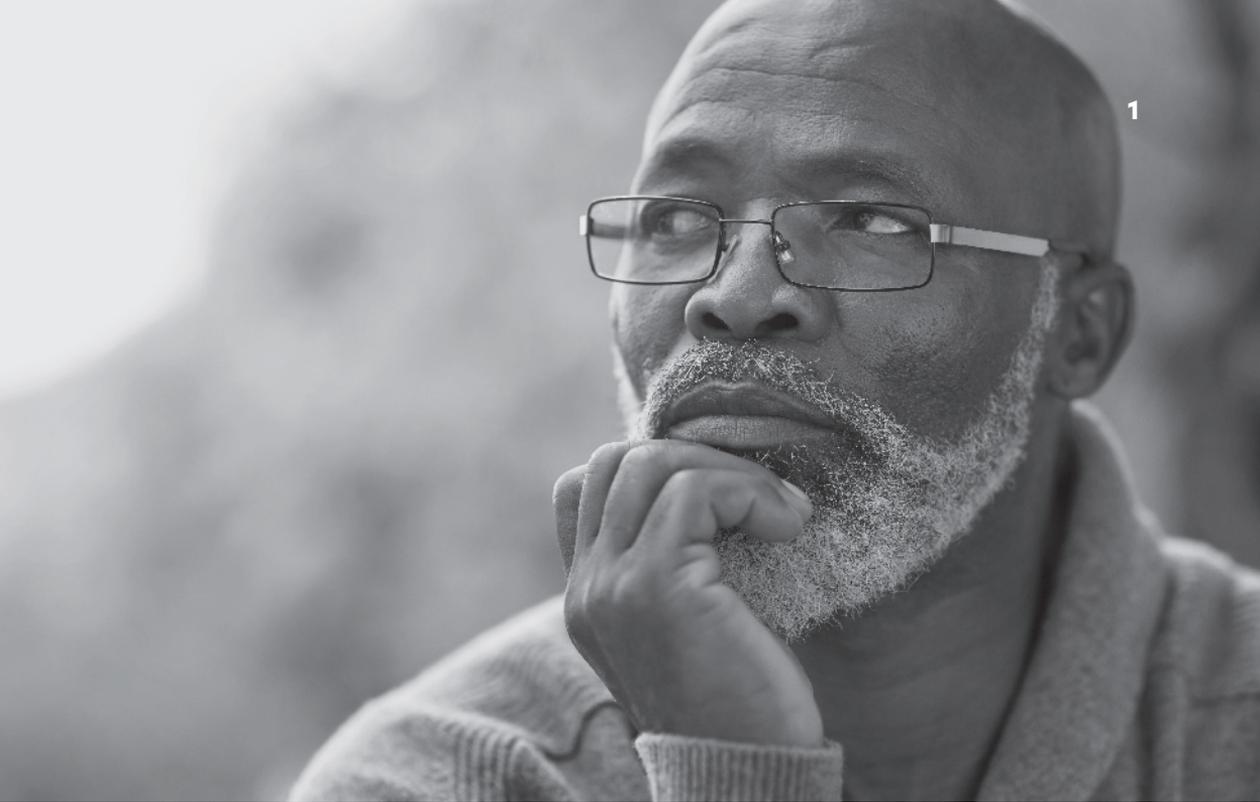
Living Your Best Life

A Guide to Parkinson's Disease



PARKINSON'S FOUNDATION RESOURCES

You can find more helpful tips for managing Parkinson's in the books, fact sheets, videos, webinars and podcasts in our PD library at [Parkinson.org/Library](https://www.parkinson.org/Library).



You may be reading this book because you or someone in your life recently received a diagnosis of Parkinson's disease (PD). Perhaps it was not so recently, but you are now reflecting more on what the diagnosis means for you. Everyone's PD story is different. Many people with PD vividly remember the moment they were diagnosed and view it as the beginning of a journey; a new life path. Often, they think back a few years and recognize subtle symptoms they missed at the time.

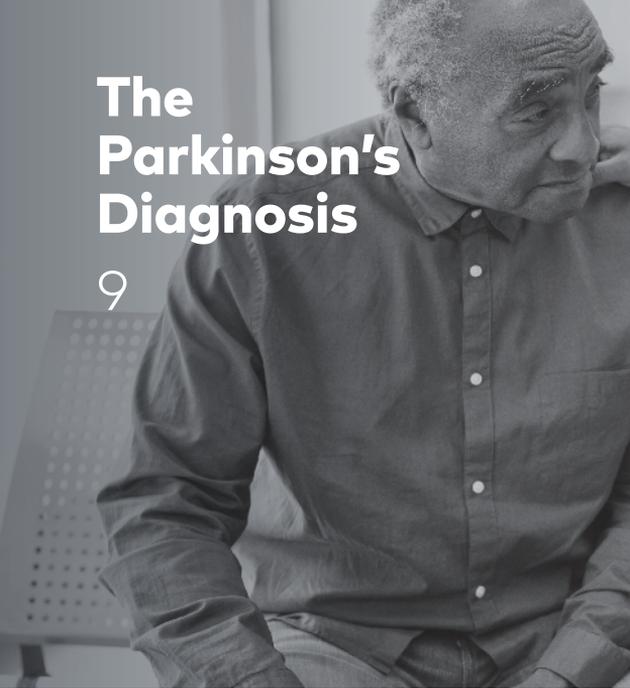
It is our hope that this book will provide you with tools to process and effectively cope with the disease, whether you were diagnosed with PD or a loved one recently shared their diagnosis with you. This book is meant to be a stepping-stone for working this diagnosis into your life and to offer an opportunity to learn how you or your loved one can live well with PD.

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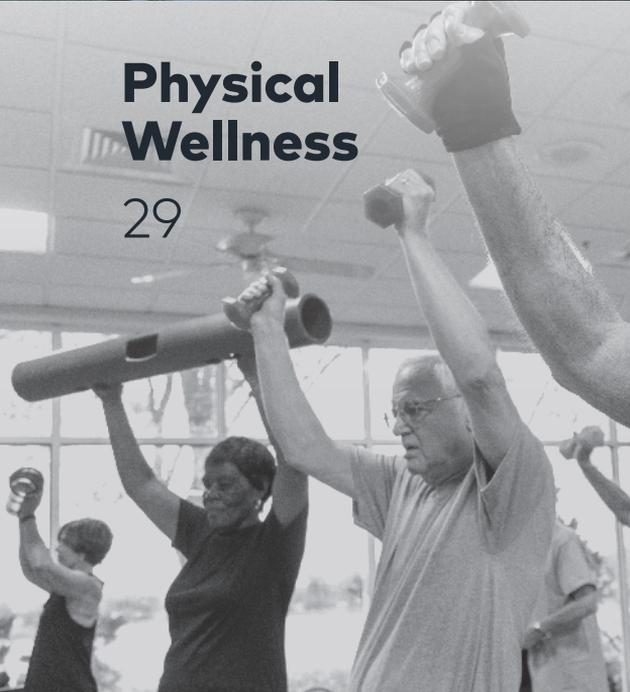
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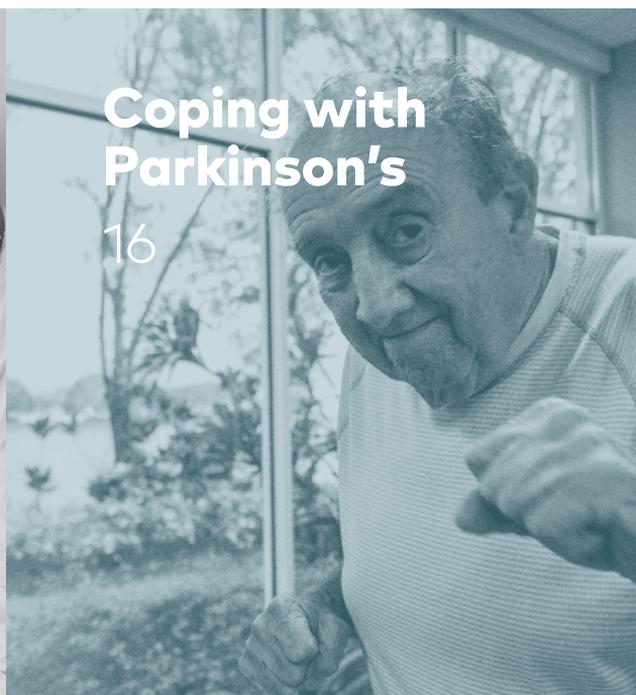
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CHAPTER ONE

About Parkinson's Disease

You may already be somewhat familiar with Parkinson's disease. This book will focus more on the aspects of living and coping with PD and less on symptoms and medications.

Briefly, PD is a complex disorder of the brain that involves the malfunction and death of brain nerve cells, called neurons, that produce a neurotransmitter, or chemical in the brain, called dopamine. Dopamine helps people control, coordinate and smooth movements, so with less dopamine in the brain people with PD experience motor symptoms, or symptoms that relate to movement, such as tremor, slowness, stiffness, difficulty controlling smaller movements, posture changes and imbalance. Since dopamine is also important for other functions of the body, speech and voice, sleep, bowel motility, cognitive function and mood may be affected. These types of symptoms are called "non-motor symptoms" and can be present along with motor symptoms. Having PD does not mean you can expect to have all of these symptoms. Each person experiences PD a little differently.

It is estimated that about one million Americans and more than 10 million people worldwide are living with PD. It is thought to impact men slightly more than women, but since it is often experienced differently by women, many suspect it may be underdiagnosed among them, as well as non-white populations. The exact cause of PD is still not known but is thought to be a combination of genetics and environmental causes in most cases.

Parkinson's is often diagnosed by a neurologist who performs an examination and reviews symptoms, medical history, medications and family history. Additional tests, such as a brain scan, may also be done. Currently there is no cure, but there are many treatments and lifestyle modifications available to effectively manage PD. These include a combination of medications, exercise, rehabilitation therapies, interventions to address safety and mental health and sometimes surgeries.

People with PD benefit from regular visits with a general neurologist or a movement disorders specialist – a neurologist who went through additional training in PD and movement disorders. During appointments with your physician, you should discuss both your motor and non-motor symptoms, especially those that are new, bothersome or concerning for you. Treatment options for these symptoms can be offered to improve your daily functioning and quality of life.

Parkinson's is considered progressive, meaning that many of the symptoms can worsen over time. The rate of progression is often hard to predict and varies from person to person. That being said, people with PD can live full, meaningful lives, especially if they manage their symptoms and safety appropriately and tap into the right care and resources.

To learn more about PD symptoms and treatment and order related resources, such as *Frequently Asked Questions* or *Medications*, visit Parkinson.org/Books or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636).

"The worst day of this disease was the day I was diagnosed. I was stunned. But the best day was when I understood that there were changes I could make in my life to help manage it and still live well. It gave me back a sense of control in my life, and some power."

PHYLLIS, 63, FIVE YEARS AFTER DIAGNOSIS

Living your best life with Parkinson's Disease

Follow Jeff's Parkinson's journey throughout this book

After 40 years as an engineer, Jeff started noticing that he was a bit slower with his work performance and since he "was the right age and was offered a good retirement package" he decided to retire. Shortly after retirement, Jeff and Betty, his wife of 39 years, moved from New York to North Carolina to live closer to their daughter and grandchildren. About eight months ago, Betty started urging Jeff to talk with his family doctor. He was still experiencing stiffness in his right arm, despite having undergone surgery for a "frozen shoulder" last year and was having intermittent shaking in his right hand. Jeff's family doctor recommended that he be evaluated for Parkinson's disease by a neurologist who specializes in movement disorders.

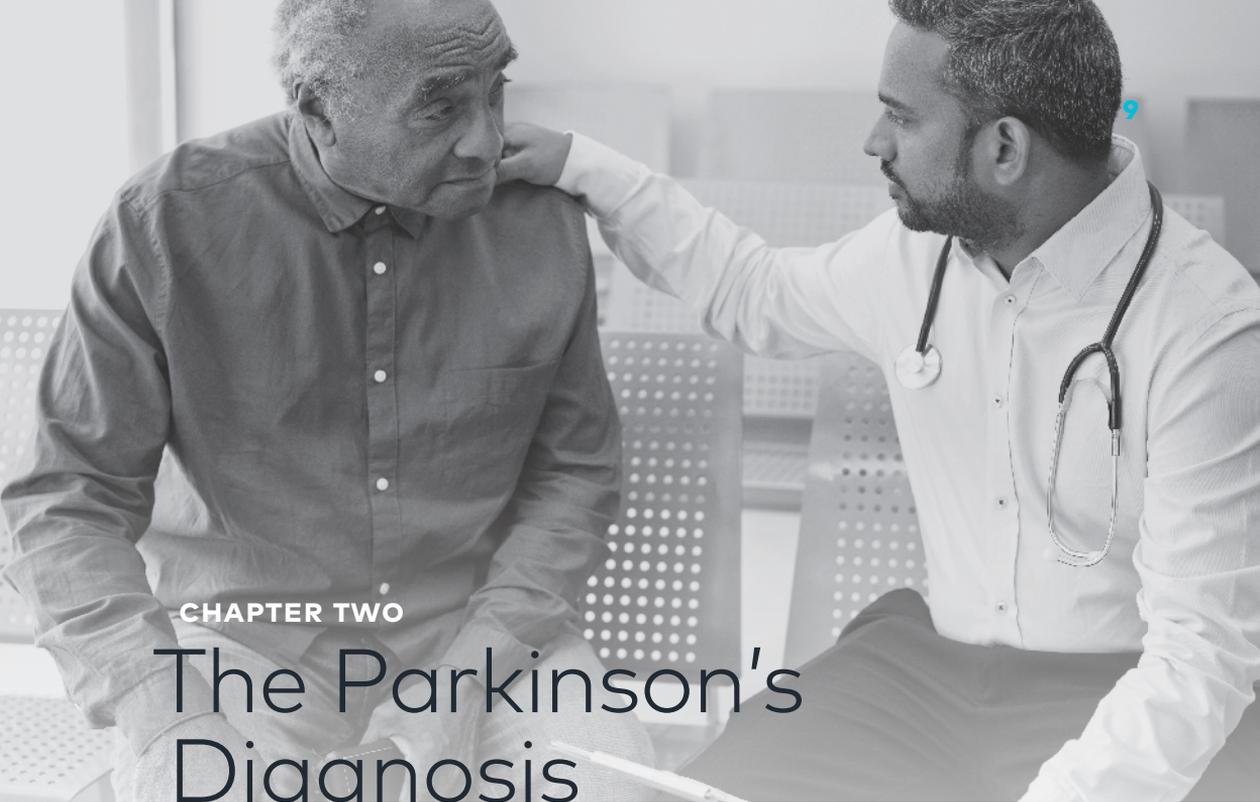
During the three months leading up to the neurology appointment, Jeff felt uneasy and anxious. "There is no one in my family diagnosed with Parkinson's. I've always been an active, healthy person. I couldn't have Parkinson's, right?" He and Betty looked up Parkinson's on the internet and became overwhelmed by the information they read, including all the possible symptoms and medications.



Jeff's story may or may not sound familiar. Everyone's PD story is different. Like Jeff, you might be thinking about what the diagnosis means for you and your family's future. You may have questions about why this happened to you. Wrapping your head around a medical diagnosis, understanding what comes with it and making related decisions – such as where to seek care and when to start medications – can leave you feeling confused and anxious. This is especially the case if you do not feel that you understand what to expect from your life with PD.

Most likely, your doctor offered some explanation of the disease. You heard words and phrases like "chronic," "progressive," "treatment," "dopamine" or "research." Perhaps you found it difficult to focus after hearing the word "Parkinson's." Now, with that visit behind you, you may think of bigger-picture questions that go beyond symptoms and treatments, which are sometimes hard to address in a medical setting.

Doctors understand that. "When I tell a patient that he or she has Parkinson's, I assume that there will be a gap between what I say and what they hear in the initial meeting," said Nina Browner, MD, Movement Disorder Specialist at University of North Carolina, Chapel Hill and co-author of this book. "I want them to understand that handling the disease will be a step-by-step process. I expect that they will have more questions as time goes by."



CHAPTER TWO

The Parkinson's Diagnosis

There is, understandably, often a desire to learn all about a new diagnosis. Finding balance between a proactive approach and wondering what lies ahead can be overwhelming, but it does not have to be. Some people share that reading about every possible PD symptom that can occur can increase their anxiety. Enhancing your own PD awareness should mean making sure you are gathering the correct information about the diagnosis, at the right time and in quantities you can process. There are many informational resources that you can access, especially online, with some being more reputable or helpful than others.

Take some time to reflect on how you like to learn new information, which may mean reading, listening to podcasts or watching educational videos, talking with someone who has been there or a combination of approaches. Consider what resources have been beneficial for you and those that have not, and when you may need to step back from immersing yourself in PD information. Your PD healthcare team, support groups and the Parkinson's Foundation Helpline (800-473-4636) can be great places to learn more and can tailor information to your preferred way of learning, whether written, oral or visual. You can also ask your neurologist, social worker or a local PD nonprofit organization if they are aware of any upcoming PD educational symposiums in the area that may be beneficial to you.

Making Treatment Decisions

When reading about PD, you may see different medications that your neurologist never mentioned to you or different techniques or surgeries that have not been discussed. Treatment decisions and medication changes are commonly based not only on the neurologist's observation during your exam, but also your own report of how your symptoms are changing with activities throughout the day and impacting your life.

One of the ways to understand whether it is time to discuss a new PD management approach is to ask yourself these questions before each neurology appointment:

- Am I able to do everything that I want to do in my life right now?
- Do I feel that my symptoms are currently well-controlled by my lifestyle and medications?

"I often suggest creating a list of things that you would like to do, or continue doing, in the next five years," said Dr. Browner. "This could be engaging with your kids or grandkids, playing golf, taking a trip, attending a family event or volunteering in the community. Whatever you choose, these activities should be fulfilling and meaningful. After making the list, periodically read it over to see whether the symptoms of PD have been interfering with participating in these activities and meeting your goals, or if you can purposefully make the time to do those activities. This can be a helpful way to assess how you are doing and determine treatment goals with your neurologist."

Sitting With Uncertainty

"What can I expect?" is one of the more burning questions for people with PD, especially those who are still new to it. Providers are often asked to pinpoint the "exact stage" of someone's Parkinson's disease or what a person's symptoms will look like in a specific number of years. We crave understanding and control – about our body and our futures. Unfortunately, there is no crystal ball for PD and healthcare providers cannot predict what any one person's unique set of symptoms, response to treatment or progression will look like. Each person's Parkinson's journey is unique, which can be both scary and comforting.

"What if?" questions are natural, but limited answers can create feelings of frustration. While it may be uncomfortable, allow yourself the space and energy to sit with these uncertainties and all of your feelings related to them. It can also be empowering to remind yourself that you are in control of many aspects of your PD. By committing to an exercise routine, taking your medications as prescribed, finding the right care providers, building your support system and being adaptive, you can positively influence your quality of life with Parkinson's.

Responding to the Diagnosis

Every person who receives a PD diagnosis responds differently to the news. Some people react with anger or depression, perhaps feeling resentful that this happened to them, hopeless about what the future may hold or regretful that they did not better appreciate life before PD. Some wonder whether certain past lifestyle choices or factors "caused" their PD. Others respond with denial, which can look different from person to person. For some, a diagnosis may mean refusing to talk or learn about PD, holding unrealistic expectations about treatment or progression or seeking out opinions from multiple doctors in a search for any possible explanation for their symptoms other than PD. Yet others may respond with positivity, or even a sense of gratitude or relief, in having a specific diagnosis, knowing they were not "imagining" symptoms and having a better understanding of what they are dealing with and more definitive answers and treatment options.

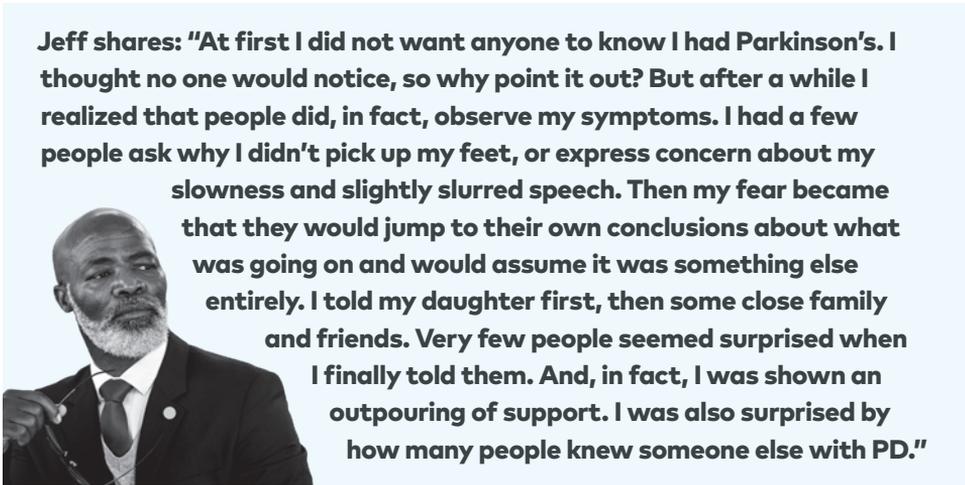
How someone reacts to their diagnosis depends on a variety of factors; these can include individual characteristics, such as age at diagnosis, whether they are still working and the strength of their support system. A person's prior experience with Parkinson's can also play a role in their

reaction. Someone who has known a person with PD who struggled with their symptoms, or someone who attributes the death of a person with PD to the disease may fear a similar experience. The way in which the diagnosis is shared can also have an impact. For example, a person who is incorrectly told by a doctor that "Nothing can be done" for PD might respond differently than someone whose doctor thoughtfully answers all of their questions, explains the diagnosis and treatment options and connects them with resources.

A person with PD and their care partner may react and cope differently. Family members and friends may feel entirely different from their loved one who is adjusting to the diagnosis. How someone views and feels about the disease will also change as time passes and their experience and symptoms evolve. Take a moment to reflect on how you reacted to the diagnosis and how your perspective of Parkinson's may have shifted over time, for better or worse, since diagnosis.

Sharing the Diagnosis

Unfortunately, there can still be stigma associated with PD. This is primarily due to general lack of understanding of the disease and misconceptions about how it will progress. This can make people with PD can be reluctant to share their diagnosis; they may have concerns that others might pity or avoid them. Or they may fear PD-associated stigma, stemming from the misconceptions of people unfamiliar with the disease. While education is key to helping others understand Parkinson's, you get to decide when and how you share your diagnosis. Everyone does this in his or her own time. Some people immediately tell their friends and family members. Others wait until they have come to terms with the diagnosis or they have symptoms they can no longer hide.



Jeff shares: "At first I did not want anyone to know I had Parkinson's. I thought no one would notice, so why point it out? But after a while I realized that people did, in fact, observe my symptoms. I had a few people ask why I didn't pick up my feet, or express concern about my slowness and slightly slurred speech. Then my fear became that they would jump to their own conclusions about what was going on and would assume it was something else entirely. I told my daughter first, then some close family and friends. Very few people seemed surprised when I finally told them. And, in fact, I was shown an outpouring of support. I was also surprised by how many people knew someone else with PD."

Disclosing the diagnosis can be an empowering experience. It provides an opportunity to bust common myths about PD. It is also a way to educate others about the diagnosis and normalize life with PD. You may want to share, in your own words, that:

- It is not a death sentence.
- There are many treatment options that can help you live a long and fulfilling life.
- Despite your symptoms, you are the same person you have always been.

You may even find yourself feeling more comfortable in your own skin when you share your diagnosis; more confident in your ability to advocate for yourself and better able to wrap your head around the reality of what Parkinson's means for you.

There is no right or wrong way to share about your PD. When discussing your diagnosis, it is OK to feel vulnerable and not to have all the answers. It is also normal to want to take a break from talking about PD or to wish people talked about it more.

If you have already disclosed your diagnosis to others, think about how it made you feel. If you have not yet shared this information with many, consider what your hesitations have been and how and when you plan to tell people. Deciding when and with whom you share your diagnosis may especially be important and tricky if you are still working. You can find more about considerations for sharing your diagnosis in the workplace in *Appendix B*.

Many people in the early stages of PD wonder whether to tell others about their diagnosis. Although no one can make this decision for you, the thoughts and experiences of others might help:

"I didn't tell for a long time because I was afraid that the revelation might jeopardize my job. Also, I didn't want other people feeling sorry for me and for my kids."

DIEGO, 51, EIGHT YEARS AFTER DIAGNOSIS

"I think people hold onto the secret longer than they need to because they want to maintain their privacy and because once you tell, it's out there and you can't take it back. I didn't tell anyone for several years. Then I sent a letter to some of my close friends, informing them. Once I did tell, I felt like a burden had been lifted and I could get some support."

BARBARA, 62, THREE YEARS AFTER DIAGNOSIS

"I told everyone, and it was very liberating."

JIM, 67, ONE YEAR AFTER DIAGNOSIS

"I kept the information from my colleagues and friends for years. It's hard enough to cope with this disease and to also cope with the tension of hiding it. When I finally "came out of the closet," it turned out that many of my friends either suspected or knew and were incredibly supportive. It was such a relief!"

JOYCE, 54, FOUR YEARS AFTER DIAGNOSIS

"When people ask about my limp, I go ahead and tell them I have PD. They're surprised because I am so young. Too many people keep this disease a secret because of embarrassment, and I think that hurts us. The more people who know about PD and how prevalent it is, the more successful fundraising and treatments may become."

ALEX, 36, TWO YEARS AFTER DIAGNOSIS

"Telling my 7-year-old grandson helped me the most. He said as long as I could still push him on the swings, it was OK. And then he gave me a hug and ran away to play. He loves me for who I am and is unphased by my PD. Reminding myself that I'm more than my diagnosis when I tell people helps me feel grounded."

HARVEY, 77, 12 YEARS AFTER DIAGNOSIS

Chapter Check In

My top three takeaways from this chapter:

1.

2.

3.

Reflection Questions:

If you are a care partner or loved one of someone with PD, you can ask yourself similar questions. Feel free to substitute "your loved one" for "you" and write your reflections below.

What do you remember about the day you were diagnosed? If you could go back and tell yourself one thing after being diagnosed, what would you say?

Who was the first person you talked to about your diagnosis? How did you feel after sharing? Did this impact how/when you shared the news with others?

Where have you gone to seek information about Parkinson's since you were diagnosed? Has this information been helpful? Is there information that is still missing for you? What is your plan to get the right information at the right time?

If you met someone who just received the diagnosis of PD today, what thoughts or advice would you share with that person?

CHAPTER THREE

Coping with Parkinson's

As a movement disorder, PD affects people in a physical way. You may notice your Parkinson's in how your body looks and moves, especially if you have visible symptoms like a tremor. Difficulty performing once seemingly minor activities you once took for granted, such as buttoning a shirt, can be frustrating. These physical changes can influence your mood and even your sense of self. Remember that PD can also affect much more than just movement. Sometimes it can be hard to express the non-physical impact of living with a chronic disease, especially if you are caught up in keeping up with medications, exercise, appointments, etc.

The following outlines some frequent coping challenges people with PD share:

- **Unpredictability:** Parkinson's is unpredictable. Symptoms can change from day to day and even over the course of a single day. People with PD often say the unpredictability is one of the hardest aspects of the disease to manage. Factors such as when you last took your medication, how much you slept the night before, your stress level and whether you exercised can impact how you feel. The disease's unpredictable nature can make it challenging to make plans; will you be up for sitting through your granddaughter's 3-hour college graduation, having lunch with your friend next Friday, or taking that cruise next spring you have been planning for six months?

What you can do: Work on getting comfortable with uncertainty. You may need to find new ways of making plans or, as many people with PD share, learn to "go with the flow" depending on how you feel on a given day.

- **Sense of control:** Human nature is to want to feel in control – of our body, decisions, plans and the future. However, a PD diagnosis can force you to recognize that you are not as in charge as you would like. This has the power to shake your beliefs around health and mortality. It is not easy to remind ourselves that none of us know what the future holds.

What you can do: Take back control! There are plenty of things you can take ownership of – your exercise routine, how you think about Parkinson's and your attitude throughout the day. It might not happen overnight, but every step toward self-empowerment is important.

- **Independence:** Similar to our need to feel in control, it is normal to want to feel that we can operate self-reliantly. We are taught from the time we are children to learn to function independently in the world. As abilities change during the progression of Parkinson's people may need to ask for, and accept, help. This transition can be difficult and can lead to vulnerable, guilty, sad, scared or angry feelings. People with PD frequently share worries of burdening their families. Remind yourself that these emotions and fears are normal and common.

What you can do: Reflect on what independence means to you. Share these thoughts with your loved ones. Consider ways you can still maintain a sense of independence while also being uplifted through the support and assistance of those around you.

- **Lifestyle:** We all become used to our lifestyles; whether it's the activities we enjoy, those we excel at, or the time it takes us to perform specific tasks. Integrating medication and exercise programs, coupled with your unique set of symptoms, may affect your routine or change how you participate in certain activities.

What you can do: Reconfigure your lifestyle. Rather than cutting out the things that are hard, make adjustments. Our friend Jeff, for example, found that while he can still play golf, he may feel more tired than he once did and often opts to play fewer holes. He also shared that due to his rigidity, he cannot lift his arms as high he once could and therefore his "golf game is a bit off." Over time, he has learned to make adaptations rather than giving up a game he loves, and his golf buddies are "more than happy to be finally winning."



- **Roles:** As you adjust to life with PD (and the normal aging process), your roles within your household and community may shift, making physical and lifestyle changes necessary. You may decide to leave the workforce. You may cut back on driving long distances or opt to stop driving altogether. You may need to ask your partner to help you with things you've done throughout your relationship, such as paying the bills or cooking. If you have done something one way for many years or your identity is tied to certain role (e.g., the family chef, the one who always takes care of everyone), changing these roles can be difficult.
-

What you can do: Create new roles. If you retire sooner than you would have liked, look for volunteer opportunities that are less demanding but still fulfilling. If you no longer have the extended family over for regular meals, can you organize a regular family walk in the park instead?

- **Identity:** How you feel in your body and how you have always viewed your health are important to how you see yourself and the world. For example, if you have always identified as "a very healthy person who has never had to take medications," this will be a big change for you. It may lead you to question why this happened to you if you have always made "the right" health decisions. It is also not always easy to incorporate a label, such as "someone with Parkinson's" into your sense of self.
-

What you can do: Reflect on your identity. As things change, it is an opportunity to look at things in new ways. Set aside time to intentionally take stock of the things that you like about yourself, the things you have accomplished and how you'd like to see yourself moving forward.

We share these commonly expressed coping challenges not to bring you down or make you fearful. Rather, we want you to know that if you find yourself confronting these challenges (and you may not), they are a normal part of going through any type of health and aging-related transition. Most importantly, you are not alone. You are entitled to recognize the changes and losses, and to even grieve over them if you need to, but we also want to highlight the importance of adapting and finding healthy coping skills as part of your journey with PD.

"I have learned that I have to adjust my morning routine before work because I'm just generally slowed down. Now it takes me an hour and 20 minutes to get ready when, for many years, it would take me exactly 50 minutes. I have just had to learn to go with it, and to give myself way more time to do things than I think I actually need."

KAREN, 65, FOUR YEARS AFTER DIAGNOSIS

Adapting to Life With Parkinson's

Living with a chronic and progressive disease like PD is no small feat. It is profound and can be life altering on many levels. You may find yourself wanting to avoid thinking about PD or seeing other people with PD, or avoiding social situations in general out of fear of being viewed differently. Alternatively, you may jump into learning all you can about PD and meeting other people with this diagnosis, or you may be somewhere in between. How you experience and react to life with Parkinson's is normal and unique to you.

We hope that you will also feel empowered knowing that how you choose to live with PD is something that is in your control. PD does not have to stop anyone from living a long, fulfilling, joyous life – it just takes a willingness to adapt to changes and challenges as they arise. Another way of thinking about this is maintaining a "flexible mindset." Adaptation can take many forms. Like Jeff, you can still play golf but perhaps fewer holes or only in the afternoon because that is when you feel the best. Or, like Karen, you may need to give yourself more time than you think you'll need to get ready in the morning. With the right adjustment and assistance, you do not have to give up important activities or aspects of your lifestyle.

Tips for healthy and effective coping with Parkinson's

- **Try to have both a hopeful and realistic attitude** towards your life with PD. While you should give yourself permission and space to feel sad or overwhelmed at times, try to balance that with putting energy into empowering yourself and finding optimism. Try to let go of what may not be working for you anymore and set small, realistic goals that will feel good to accomplish.
- **Use humor** – life is too short to not laugh at yourself, even in sad or hard situations! It may even open you up to viewing something in a different light.
- **Don't let your life revolve around PD but do not deny or avoid it either.** This can be a delicate balance, but there is space between the two extremes. Find time where you are focused on addressing your PD and time where you can immerse yourself in the other aspects of who you are. It is possible to incorporate PD into your identity without letting it define you.
- **Continue to participate in enjoyable, meaningful activities** even if you need to modify them instead of getting discouraged and giving things up as they become harder to do. If you find yourself losing interest in hobbies that you used to enjoy or are no longer finding joy, inform a loved one or someone on your healthcare team because this can be a sign of depression or apathy, both common symptoms of PD that can be addressed.
- **Be your own advocate.** You understand your experience with PD better than anyone else. Speak up for your needs and beliefs in a constructive way. You may need to remind people that they can direct questions to you if you're finding that they are turning to your care partner to ask about how you are doing. You can share with your partner that you appreciate when they give you the time you need to respond.
- **Be kind to yourself.** Try to not to hold on to judgments of your symptoms or what you think you should have done differently in the past. You are doing the best you can. You have never been faced with this situation before and you are reacting to it and giving it the best you can, given the circumstances. Being kind also means cultivating patience with yourself – to get through a task at your own pace and to give yourself space and time to sit with your feelings and experiences around PD.

This is all a process. Effective coping looks different for everyone and changes over time. Sometimes chronic and progressive diseases leave people feeling helpless at times, but most people with PD, especially after digesting the diagnosis, share that they surprised themselves with their resilience and were able to establish a "new normal". It is then that there are opportunities to make meaning out of the PD journey.

"Once I stopped completely dwelling on the fear and shock of having to live with PD, and I took time to reflect on my experience with it since the time I was diagnosed, I realized it actually gave me a lot of gifts. It made me value my time and my family's support more. I met people and tried things I wouldn't have otherwise. It's helped me be more mindful and grateful."

DARRYL, 74, EIGHT YEARS AFTER DIAGNOSIS

Making Meaning

In a counseling setting, the concept of 'making meaning' is used to help people how to intentionally shape the way that they look at situations in their lives.

How you experience PD and adjust your life to meet your needs will most likely evolve over time. You can intentionally decide to make meaning out of this experience and find purpose in it. Every once in a while, we encourage you to ask yourself how you are doing and what you have lost, gained and learned about life and yourself through your experience with PD. Consider what you are most grateful for and reflect on how you can continuously strive for improvement and show up for yourself and those you love. Like any curveball that life may throw you, there is much personal growth and resilience that can be discovered in living with PD.

Some people impacted by PD also find meaning in connecting with "giving back" to the Parkinson's community. Examples include starting a support group, participating in PD research or becoming involved in a PD fundraising event. You can read more about "giving back" in *Appendix C*.

Continuing to Connect

- **Socialization.** Even if you find it difficult while adjusting to life with Parkinson's, continuing to build meaningful connections and finding time for interaction with family and friends is essential to your well-being. If you notice yourself socializing less, ask yourself why and how you can address it. For example, eating at restaurants can become stressful if your friends and family have trouble hearing you in the noisy space, if you have trouble navigating through the tight space between tables or if your eating habits have changed. If you find yourself uncomfortable eating in a restaurant, invite friends to your house for take-out or a home-cooked meal instead.
- **Care partners.** You do not have to go through this experience alone. Adapting to life with Parkinson's should be a partnership between the person with PD and hopefully at least one other person. Care partners are those who walk alongside you, providing needed care and support throughout your Parkinson's journey. This can be physical (giving you an arm to lean on when you put on your socks), emotional (listening to your fears and brainstorming ideas) and logistical (attending doctor appointments, driving and running errands). Often a care partner is a romantic partner, spouse or an adult child, but it can also be a good friend, sibling, grandchild, professional or another trusted person in your life. You may even have several care partners who take on different roles. However, not everyone has someone in their lives who would naturally become a primary care partner, and others may have a partner who is unwilling or unable to provide this care. Take the opportunity to talk with those in your life about their comfort, abilities and feelings related to care roles in PD.

"I have had to learn what it means to be a Parkinson's care partner while also still being his wife. We have had to adjust how we plan ahead, and we try to talk things through, but we've always done that throughout our marriage. I need to purposely set aside time for my own self-care and find ways that he can support me while I support his Parkinson's."

RUTH, WIFE OF A PERSON WITH PD

Care partners can read more tips in the Parkinson's Foundation resource *Coping & Caring: A Caregiver's Guide* to Parkinson's Disease.

To order care partner-related resources visit Parkinson.org/Books or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.

- **Communication.** Communicating about Parkinson's throughout your journey is a critical aspect of living well with the disease. Open and honest communication can be uncomfortable or difficult. It can be especially challenging if your speech or voice is impacted by the disease. Good communication takes intention and adaptation. Whether you are a person with PD or someone who cares for that person, allow time to have conversations about your PD experience; time to share your fears, feelings and needs. You can read more about considerations for future planning in *Appendix D*.
- **Support Groups.** Many people with PD and their care partners find comfort in meeting others who are also affected by PD. Support groups are not for everyone, and some people avoid them due to a fear of "seeing people who are more advanced." It can be helpful to call the leader of the group and ask about who typically attends to see if they are in the same age range and stage as you are.

After attending at least one or two support group meetings, many people with PD find themselves relieved and validated to be in the company of people with whom they can relate. You may be surprised to learn that you are not alone in the emotions or challenges you have experienced with PD. Support groups are also a great place to learn symptom management tips and get resource recommendations on everything from books and exercise programs to tips for easier everyday living.

"I don't care how tired I am or how bad the weather, I never miss the monthly meeting of my support group. It's the one place where I don't have to be on my guard, can say whatever I want and feel free to just be me. It's my anchor."

SALLY, 59, FIVE YEARS AFTER DIAGNOSIS

Each support group operates a little differently. Some are very focused on sharing, while others primarily offer educational lectures. Many are a mix of both. Certain support groups are for specific audiences, providing space for care partners, for women with PD or for those with young-onset PD. Groups also vary in size. Similar to choosing the right doctor, it is important to find a support group that is a good fit for your needs. If you are looking for a support group near you, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or ask your neurologist or clinical social worker.

If there are no area Parkinson's disease support groups, area offerings do not meet your needs or you are uncomfortable in a group setting, ask a member of your healthcare team if they can connect you with another person or two with Parkinson's on a more individual level. Online groups and social media pages can also offer PD community connections. Parkinson's disease educational and fundraising events are another outlet to engage with others living with PD.

"Waiting in the reception area to see my doctor, I got to talking with another woman. She invited me to join her support group. I declined, but we did make a date to meet for lunch at a museum. At lunch, we were joined by a third woman ... and later a fourth. So, I guess I'm in a support group in spite of myself. I really like these women. It's also freeing not to have to hide my symptoms, and just focus on the conversation."

ELAINE, 52, THREE YEARS AFTER DIAGNOSIS

- **Intimacy.** If you have a romantic or sexual partner in your life, staying connected can also mean continuing to find ways to be intimate with one another. PD symptoms, medication side effects and the normal aging process can all sometimes impact sexual function. Shedding Parkinson's stressors to become intimate can also be challenging. It can take time to adjust to how you view and move your body or how you and your partner interact, and this can make intimacy more difficult. Keep the lines of communication with your partner open, even if it is not always comfortable. Talk about what you like, what you miss, what works and what does not, and how you both feel about these things. Many partners want to continue to experience sexual relationships the same as they always did, but, like so many other aspects of PD, you may need to make adaptations as your needs change, and that is OK. Intimacy, or expressing affection and closeness, can go beyond physical or sexual relationships. Even if your sexual relationship has been altered, you can still find ways to connect intimately. Examples include holding hands, cuddling, sensual touches that may or may not lead to sex or end in orgasm, laughing together, complimenting each other, going on dates, reminiscing, verbally expressing love or gratitude and finding time to connect when you are not talking or thinking about PD.

To learn more about intimacy-related resources, such books, fact sheets, podcasts and webinars, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.

Mood and Mental Health

One of the keys to living your best with PD is to address both the physical and mental aspects of wellness, as the two are inextricably tied for most people. This goes beyond the coping challenges and skills discussed previously in this chapter.

An important step to mental wellness is awareness of mood challenges that can arise with PD. The same chemicals in the brain that are involved in the regulation of movements also influence mood. In fact, the *Parkinson's Outcomes Project* has found that more than 50% of people with PD describe experiencing symptoms and feelings of depression and about 30% report an anxiety disorder, such as generalized anxiety, agoraphobia (fear of people, places or situations that may cause anxiety) and panic attacks. Depression and anxiety can also worsen certain PD symptoms like tremor and freezing.

Signs of depression can include:

- Feeling slower or restless
- Decreased interest or pleasure in daily activities
- Poor attention and difficulty concentrating
- Decreased energy or fatigue
- Changes in appetite
- Changes in sleep (insomnia or oversleeping)
- Feelings of guilt, blame or worthlessness
- Thoughts of death or suicide

Signs of anxiety can include:

- Excessive fear and worry
- Uncontrollable or unwanted thoughts
- Sudden waves of terror
- Nightmares
- Ritualistic behaviors
- Problems sleeping
- Pounding heart
- Cold and sweaty hands
- Dizziness
- Nausea

All of these, of course, can also overlap with PD symptoms, so be sure to look out for a new development or an increase in any of these signs of depression or anxiety.

The good news is that, just like other symptoms of PD, mood can be successfully treated. Research finds that certain mood medications can be beneficial, especially in addition to participating in mental health counseling. Other lifestyle changes, including exercise, nutrition, engagement in meaningful activities and increased social support also make a huge difference in managing mood changes.

PD can also cause apathy, or a decreased drive or desire to participate in activities. It can be difficult to distinguish between apathy caused by depression and stand-alone apathy. Many times, people with apathy will not feel motivated to initiate an activity, such as exercise or social plans. They will not be excited about the prospect of doing activities but will enjoy them once they are engaged, often as the result of encouragement from a partner. Care partners often must be very thoughtful about helping their loved one overcome apathy without stepping into a "parenting" role.

Unfortunately, many mood disorders go unreported. This may be because people do not recognize the signs, they feel ashamed or embarrassed to share them or because clinicians are not asking the right questions about mood. Now that you know that mood symptoms are common with PD and that they are treatable, be sure that you and your loved ones monitor your mood over time and report any changes or concerns to your medical team. Mood changes should not have to impact your motor symptoms and your enjoyment of life. Be sure to address mood symptoms as early as possible. Ask your doctor or clinical social worker what options you can explore to address your mood.

Even if you are not experiencing anxiety or depression, it can still be helpful to work with a mental health counselor to process living with PD and to build coping skills through your journey with PD. It can be beneficial to have an unbiased professional help you sort through what that means for you. This also applies to PD care partners and anyone else in your life affected by the changes caused by PD.

To learn more about mood-related resources, such as books, fact sheets, podcasts and webinars, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.

Chapter Check In

My top three takeaways from this chapter:

1.

2.

3.

Reflection Questions:

If you are a care partner or loved one of someone with PD reading this book, you can ask yourself similar questions. Feel free to substitute "your loved one" for "you" and write your reflections below.

How has your life changed since receiving a PD diagnosis? What have you lost, gained, and learned about life and yourself?

Who would you define as your "PD care partner"? Who would you like to be able to turn to for assistance or support? Is that person aware that you view them this way and are they comfortable with that role?

Have you ever dealt with mental health challenges before PD?

If so, what did you do to cope? If not, what concerns do you have about seeking help should you need it? Who in your life do you think can help you identify changes you may not immediately recognize?

Who is in your circle of support? Are you openly talking about PD, including current and future care needs? Are you all coping differently, or have you remained on the same page in most areas?

CHAPTER FOUR

Physical Wellness

You may be wondering how you can live well with a chronic disease. At the Parkinson's Foundation, our mission is to make life better for people with PD by improving care and advancing research toward a cure. In this chapter, we will provide an introduction on how to get the best care and strive towards physical wellness.

Keep Moving!

Establishing a regular exercise routine is a first critical step for physical wellness with PD. Research from the Parkinson's Foundation *Parkinson's Outcomes Project* shows that starting an exercise routine and consistently exercising have positive effects on self-reported health-related quality of life and mobility. It is better to start earlier, but it is never too late. Studies have shown that exercise and physical therapy can improve many aspects of Parkinson's. Aside from taking medications on time, exercise is the single most important activity you can do to manage Parkinson's and lead the best possible life.

Research has measured the following Parkinson's-fighting changes in the brains of animals that exercise:

- More effective use of dopamine by brain cells
- Growth of new blood vessels, which helps brain cells get the oxygen and nutrients they need to stay healthy and participate in the activities of thinking
- Improved use of energy by brain cells (better metabolism)
- Increased release of special proteins that strengthen connections (synapses) between brain cells, and growth of new connections
- Reduced potentially harmful effects of the immune system (less inflammation)
- Growth of new brain cells

Data from the *Parkinson's Outcomes Project* confirms that 2.5 hours of weekly exercise is the target amount for people with Parkinson's to lead a better quality of life. This means 30 minutes of exercise five times a week. You can be creative and work around any physical limitations. For example, walk for 10 minutes three times a day instead of one 30-minute walk.



Aerobic exercise such as boxing, dancing, water aerobics and riding a stationary bike are popular among people with PD. Many people also enjoy yoga, Pilates, pickleball and other activities. Any exercise can help as long as it is safe based on your Parkinson's symptoms and other health factors. Always check with your doctors and/or physical therapist before starting an exercise program and make sure to **find something you enjoy and that motivates you**. Choosing something that you actually want to do will make it easier to incorporate regular physical activity into your lifestyle. If you were never a big exerciser in the past, now is a great time to start.

It is also important to balance exercise with times of relaxation. Listen to your body. If you are concerned that you might be overdoing it, cut back and consult with your physical therapist.

"I did not enjoy going to the gym and the at-home exercise videos didn't do it for me. I just kept putting them off. Finally, I started attending a few local group exercise classes – one specifically for Parkinson's, one for balance at the senior center and one general power yoga class – and that made all the difference. It gave me a routine to stick to. I also have a friend who takes walks with me, and I've become friendly with some people in the classes, so the social aspect has also been really gratifying."

BILL, 80, NINE YEARS AFTER DIAGNOSIS

To learn more about exercise-related resources, such books, fact sheets, podcasts and webinars, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.

Take Care of Your Whole Self

Sometimes it is easy to forget about other aspects of health when so much of the focus is on PD. It is also common to attribute all aches and pains to PD when it could be something else entirely. Discuss any changes with your family doctor periodically to make sure you are not missing anything unrelated to your Parkinson's. It is also natural to want to tease apart what is PD versus "normal aging" or something else. Remind yourself that it is usually not that easy to do, and it is important to recognize and address the concerns as they arise, regardless of the exact cause. Body systems are often linked, so it can be helpful to ask your providers about the interaction between PD and other health issues you may have, such as arthritis or diabetes. Additionally, take time to assess your level of stress, related to PD or not, and how it is impacting your physical and mental well-being.

Building the Best Care Team

Finding the right care for optimal management of PD, as well as your peace of mind, is essential! Since PD is such a complex disease, you will want to consider adding many different members to your Parkinson's healthcare team to help with management over time. This will include different types of doctors and nurses, as well as rehabilitation therapists and specialists in mental health care, depending on what symptoms are most impactful in your day-to-day life. Your needs and care goals will change as the disease progresses but knowing who you can turn to on your care team can help you when new needs arise.

Finding the Right Doctor

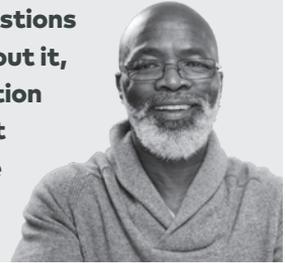
The doctors who specialize in diseases that affect the brain are called neurologists. A small subset of these neurologists, called movement disorder specialists, have additional training to better identify and address different brain diseases specifically related to movement. A movement disorder specialist is an expert in all aspects of PD and other "movement disorders" (e.g., essential tremor, dystonia, Huntington's disease). They are very knowledgeable regarding the full range of treatment options and are familiar with cutting-edge clinical and scientific research. They make medication adjustments, provide referrals to rehabilitation therapists and other specialists and monitor how symptoms progress over time.

Most people with Parkinson's will see their neurologist about every 4-6 months, but this can be more or less often depending on their unique PD symptoms and needs. Some people choose to seek care from a movement disorders specialist while others feel very comfortable with a general neurologist. In certain areas, it can be more difficult to find movement disorder specialists, or these specialized neurologists may have less appointment availability. In those cases, people sometimes opt to see a movement disorders specialist once every year or two for consultation but have more regular appointments with a local general neurologist. No matter what, the ideal PD doctor is available to provide advice and care and is responsive during times of need.

Locating a qualified physician is a first step; next consider whether the provider you have seen is the right doctor for you. Keep in mind that you will be working with this specialist for many years. If the doctor-patient fit does not feel right to you, it is alright — even recommended — to seek

a different match. You also have the right to pursue a second opinion on your diagnosis or treatment plan, even if you decide to continue seeing your original doctor.

Jeff shares: "I was so anxious after my family doctor told me that he suspected I had Parkinson's and wanted me to see a neurologist. After I saw the movement disorders specialist, I felt a great sense of relief. She took time to answer all of my questions about Parkinson's and gave me literature to read about it, which was a lot better than some of the misinformation I had read about online. I finally feel like I have a point person to turn to every six months who will guide me through this."



The Parkinson's Healthcare Team – Beyond the Neurologist

We recommend that you learn about the healthcare professionals in your area who can help you manage your PD and maximize your quality of life. Once you know who is available, you can build a supportive healthcare team to turn to when additional help is needed. It takes more than a neurologist or movement disorder specialist to manage PD well-being. You will most likely see some of these other clinicians more often than the neurologist. Clinicians can communicate with each other regarding your care to take more of a team approach or at least keep one another informed.

- **Primary care providers (PCPs)**, also called general practitioners or "family doctors", will continue to monitor your general health and can coordinate your overall care. PCPs collaborate with your other clinicians (including a neurologist), refer you to specialists when necessary and help you when you have an acute illness or other issue unrelated to PD. Some people choose to have their primary care providers manage their Parkinson's disease, instead of a neurologist, especially if they specialize in geriatrics or if the person with Parkinson's lives in a remote area without access to a neurologist. However, while very knowledgeable, remember that PCPs are not specialized in the care of brain disorders like neurologists are. It can get confusing when primary care providers change PD-related medications prior to consulting a neurologist.

- **Physician assistants (PAs) and nursing professionals**, such as nurse practitioners (NPs), have advanced degrees and work at many neurology and primary care provider clinics. A PA, NP or a registered nurse may be a primary contact for you, and you may even see them during some of your neurology follow-up appointments. They are very helpful with check-ins and medication refills and can also connect you to resources.
- **Pharmacists** can assist you to keep track of and understand your PD medications. Be sure to ask your pharmacist about major side effects to watch for with new medications, or potential interactions between your PD medications and other medicines you may be taking. Pharmacists, sometimes called "pharmacy counselors," can tell you your out-of-pocket medications costs based on your insurance and may be able to refer you to prescription assistance programs. Pharmacists work at the drug store where you pick up your medications, but sometimes outpatient neurology clinics or PCP offices also have on-site pharmacists – ask your doctor.
- **Clinical social workers** address the non-medical aspects of Parkinson's, including your mental health and support system. They view each person with PD through the lens of strengths, dignity, diversity and right to self-determination. They can connect you to community resources, such as support groups, exercise programs, transportation and meal options, PD-specialized rehabilitation therapists and in-home and long-term care. They can also address care partner and family support needs and some may provide short- or longer-term mental health counseling.
- **Mental health professionals:**
 - **Psychiatrists** are medical doctors who specialize in the treatment of mental health concerns, including depression, anxiety, suicidal thoughts and dementia. They can prescribe medications for mood and many of them offer therapy as well.
 - **Neuropsychologists** have expertise in behavioral and cognitive changes and can help tease apart their relation to mood and other factors, like fatigue.
 - **Psychologists, counselors and therapists** provide therapeutic advice and counseling around PD, including processing the diagnosis and living with the disease, teaching coping skills and addressing anxiety and depression.

- **Speech-language pathologists (SLPs)** assess and manage speech and voice quality and production, and teach various vocal exercises. SLPs certified in the intensive speech therapy program, Lee Silverman Voice Treatment (LSVT) LOUD, can specifically address some of the unique PD-associated vocal changes, such as soft, low speech. SLPs can also incorporate breath support techniques and the use of pacing boards and evaluate for communication devices.

Despite their title, SLPs can address much more than speech. They can diagnose, help evaluate and treat swallowing concerns and may make diet modification recommendations if appropriate. SLPs also perform cognitive testing. They may work closely with neuropsychologists and can follow up with compensatory strategy training to help you and your care partner adapt to cognitive changes in your home setting.

- **Physical therapists (PTs) and PT assistants** will evaluate and treat your gait, balance, strength, walking safety and ease of transferring. They can establish an appropriate home exercise routine for your functioning and goals, as well as make recommendations regarding mobility equipment when necessary. LSVT BIG and Parkinson's Wellness Recovery (PWR!) are two intensive, PD-specific programs. Program-certified PTs may incorporate them into treatment to address the unique smaller movements and balance challenges associated with PD.
- **Occupational therapists (OTs) and OT assistants** are also critical in the management of daily functional tasks, or activities. They can help improve your performance of "Activities of Daily Living", such as eating, dressing, bathing, toileting, bed mobility. They can also outline strategies to improve your "Instrumental Activities of Daily Living", including writing, using the phone, cooking and medication management. It's also important to address your ease of participation in hobbies you enjoy, like sewing or reading. Occupational therapists teach strategies and recommend equipment to help you continue enjoying such activities. Sometimes OTs can also assess safety within the home environment or perform driving evaluations. The PD-specific LSVT BIG and PWR! programs also offer certifications for occupational therapists.
- **Exercise professionals** may include personal trainers, integrative health coaches and group exercise instructors. These specialists can help you stick to a regular physical activity routine, which is a key to living well with PD. Look for an exercise professional with PD training or experience if possible. Some may lead PD-specific exercise classes in your community.

There are many other healthcare professionals with whom you may work over the course of your Parkinson's disease. These may include urologists, neuro-ophthalmologists, gastroenterologists, sleep disorders specialists, music therapists and nutritionists or dieticians. You may be referred to them for specific symptoms that arise.

It is worthwhile to try to tap into specialized care for PD by seeking out clinicians who have undergone specific training or certifications in PD, such as the Parkinson's Foundation's Allied Team Training for Parkinson's (ATTP®), LSVT or PWR! and who work with people with PD on a regular basis. For example, you will most likely notice better results with your PD-related walking concerns when working with a PD-trained physical therapist than a sports injury-focused physical therapist. Ask your neurologist or PD social worker if they know of clinicians within their center or your local area who are particularly PD knowledgeable. If they're not sure, call the Parkinson's Foundation Helpline at 800-4PD-INFO (473-4636).

It is also ideal to find clinicians who work together in a multidisciplinary setting. When working with a team of clinicians is not possible, try to work with clinicians who are connected with the local PD community as they will be aware of nearby support groups, exercise programs, clinicians, educational programs, or other resources. If there are no PD-trained clinicians in your area, you may want to seek out neuro-specialized or geriatric-focused care.

"Something that has been really important for me has been to prepare for all of my Parkinson's appointments, especially with my neurologist. Depending on where you go, an appointment with a neurologist can be 15 to 60 minutes, which is never enough time to explain and ask about everything that has happened in the last few months, especially on top of the exam the neurologist has to do. Plus, I used to have a tendency to remember a burning question as I was walking out of the appointment. So now what I do is write out and bring a list of my top three to five concerns and questions that I want to try to go over."

EILEEN, 68, THREE YEARS AFTER DIAGNOSIS

Tips for working with your healthcare team

- **Take notes in between appointments**, including questions, concerns and new symptoms that arise, and new goals that you set, so that you are sure to not forget anything you want to discuss in the often-limited time you have with the provider.
- **Take a list of your current medications** with you to all of your doctor's appointments, including how and when you take them. You may even be encouraged to bring the original prescription bottles with you. If you have received your free *Aware in Care* kit through the Parkinson's Foundation to help you stay safe in the hospital, this kit contains a medications list for you to keep up to date. You can order your kit at AwareInCare.org.
- **Try to request morning appointments** to reduce your chance of waiting in the waiting room for a long time.
- **Be patient when asking questions between appointments.** It could take a few days to hear back. Sometimes people don't allow enough time after they leave a message with a provider's office, calling back a few hours later saying, "I haven't heard back from my doctor yet" while he or she may have been in clinic all day. If you have not received a response within three days, try contacting the office again. Ask yourself whether your question is non-urgent. Can it wait until your next appointment? Would it be better suited to an in-person conversation? There is usually a contact number or online system for more urgent or timely questions, or depending on how urgent the situation is, you may be encouraged to go to your primary care doctor, an urgent care clinic or even the emergency room.
- **Take your PD medications on time, as prescribed by your doctor** to optimize your functioning and quality of life. To reduce your risk of running out of pills, do not wait until you are low on your medication supply before asking your doctor's office to send in a new prescription.
- **Call the clinic as soon as possible if you feel you need an appointment.** Sometimes there is no availability for a few months, especially with neurologists or rehabilitation therapists. It is often helpful to schedule follow-up appointments when you check out.

- **If possible, take a support person with you to your appointments.** You will be asked a number of questions and given a lot of information, so it can be helpful to have a second person there to assist if needed. The clinician will also likely appreciate hearing another perspective on how you have been doing.
- **Be candid about how you have been doing.** Too often people respond with, "Oh, I'm fine" when asked how they are, but then the support person speaks up in disagreement or they call the office a few days later saying, "I forgot to mention all of these concerns I have been having." Similarly, be honest with your provider about whether you have been taking your medications on time, as prescribed, and keeping up with the rest of your plan of care and recommendations. Healthcare professionals can best assist you when they are aware of your actual functioning and concerns.
- **Advocate for yourself.** Only you know how you have been feeling and what your priorities are. If you are bothered by your soft, low voice right now but your neurologist has not mentioned speech therapy, you can bring it up and ask for a referral.
- **Encourage the clinicians who address your PD to share their notes with one another.** If you are seeing multiple clinicians within the same healthcare system, they may be able to read one another's notes, but this is not always the case. If you feel it would be beneficial to your multidisciplinary care to have your primary care doctor read your physical therapy notes, or for your psychiatrist to run a question regarding a medication by your neurologist, you should advocate for that. You may need to complete a medical release form before they can do so.
- **Find the right care.** Choose providers with whom you feel you have good chemistry and you trust to manage your symptoms over time. Try to find a healthcare team you feel understands and respects your concerns and goals. Know that you have the right to switch providers if you need another perspective or if your needs are not being met.

To learn more about healthcare team-related resources, such as books, fact sheets, podcasts and webinars, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.

More on Rehabilitation Therapies

Rehabilitation is frequently thought about as part of a recovery process, such as for an injury. With Parkinson's, it is viewed as a necessary way to adapt to constantly changing symptoms. Rehabilitation most often includes physical, occupational and speech therapies.

Participation in rehabilitation therapies can and should be done repeatedly over the course of PD in order to tailor the exercises and strategies to each stage of the disease. For example, occupational therapy can help with difficulties such as writing or buttoning your shirt following your initial diagnosis; years later you may find it can help ease cooking concerns or balance issues when dressing.

Sometimes people wait until a symptom or concern is "bad enough" or they are "farther into the disease" before seeking a referral for rehabilitation therapies. However, research shows early participation offers great benefit from a preventative standpoint. You can talk to your doctor about getting a baseline physical therapy assessment soon after your diagnosis – before symptoms might impact quality of life – and continue with periodic reassessment.

"I was only familiar with rehabilitation due to a few sessions with a physical therapist after a car accident. I did not think of it as something you could do for Parkinson's. The physical therapist taught me exercises that were specific to my symptoms and goals. I continue these at home about five days per week and I can't tell you the world of difference they have made in my coordination and my confidence in walking. I also now understand what types of exercise at the gym are more appropriate for me and what are not."

DAVE, 48, TWO YEARS AFTER DIAGNOSIS

To learn more about rehabilitation therapy-related resources, such books, fact sheets, podcasts and webinars, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or visit Parkinson.org.

Chapter Check In

My top three takeaways from this chapter:

- 1.
- 2.
- 3.

Reflection Questions:

Do you feel respected by your Parkinson's doctor? Are you comfortable speaking about the more sensitive changes you're experiencing related to sexuality or changes in mood?

Are questions answered to your satisfaction at appointments? Do you come away from a visit feeling that you have not been taken seriously? Can you get in touch with the doctor between visits if urgent needs or questions arise?

Other than your neurologist, who else makes up your PD healthcare team? How frequently do you have appointments, and do you feel that is sufficient? When do you know it is time to turn to them? Who else can you add to your team?

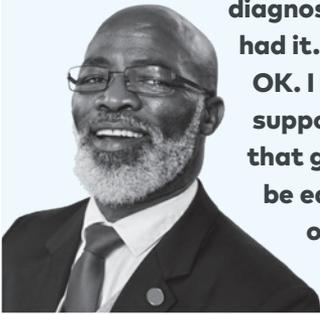
CHAPTER FIVE

Summary

Parkinson's disease is a complex, chronic and progressive disease that can cause both motor and non-motor symptoms. Specialized attention from a team of healthcare professionals is critical for maintaining quality of life with PD over time. Although PD is classified as a "movement disorder", related changes in family roles, sense of identity and plans for the future can have an emotional and psychological impact on you and your loved ones. While there are many PD management strategies – including medications, rehabilitation therapies, dietary changes and exercise – digesting the diagnosis, learning about it and incorporating PD into your life is a process.

Every person experiences PD differently. Be intentional about checking in with both yourself and your loved ones throughout this journey so that you can continuously assess how you are feeling, what you have learned and what you need. Adapting to life with PD also means building a support system, tapping into the right resources and establishing effective coping strategies.

People can and do live well with Parkinson's, despite the challenges and changes that arise.



Jeff shares: "There are a lot more emotions involved in having Parkinson's than I had anticipated. I'm feeling different about the diagnosis now compared to when I was first told I had it. I'm sure that will keep changing and that is OK. I know there are others I can turn to for advice, support and assistance for whatever might arise, and that gives me a sense of calm. I know it won't always be easy, but I want to face this experience with an open mind and focus on what is in my control and everything I have to be thankful for."

APPENDIX A

The Parkinson's Foundation Newly Diagnosed Campaign: Building a Better Life with Parkinson's

To reach more newly diagnosed people, the Parkinson's Foundation has launched a new campaign, "Newly Diagnosed: Building a Better Life with Parkinson's," to arm people who are newly diagnosed with the knowledge, tools and resources they need as they begin their own personal journey with the disease. Visit Parkinson.org/NewlyDiagnosed for more resources, expert advice and a new online community for people with Parkinson's, family members and care partners to build a better life with Parkinson's.

On the next page, you'll find the five steps we recommend to everyone who has received a PD diagnosis. These five steps – in any order that works for you – will help you get started on your journey to living well with Parkinson's. someone newly diagnosed.



1. Think about what is most important to you

Based on what's important to you, determine your personal goals and priorities. This will help you create an action plan to continue doing the things you love and care about most.

2. Find someone you can talk to

When you're ready, we encourage you to talk to someone, whether that is calling our Helpline, 1.800.4PD.INFO (473.4636) to ask questions, or reaching out to a family member or friend, or another person with Parkinson's. Don't isolate yourself, you are not alone.

3. Create healthy habits

Choosing healthy foods may help your medications work better and improve your energy. Getting enough sleep can help your body and brain recharge. Small changes can make a big difference and creating a healthy routine may help you feel better. Learn from others through our online community, [Parkinson.org/NewlyDiagnosed](https://www.parkinson.org/NewlyDiagnosed).

4. Be active in whatever way works best for you

It's a fact: exercise can improve your quality of life. Visit our website, [Parkinson.org/NewlyDiagnosed](https://www.parkinson.org/NewlyDiagnosed), to learn about the importance of exercise and find a Moving Day event near you. Get up, get out there, get active.

5. Find a doctor who is an expert in Parkinson's disease

Call our Helpline to find expert care in your area. Look for a neurologist who treats people with Parkinson's, and when possible, a movement disorder specialist.

APPENDIX B

Sharing Your Diagnosis in the Workplace

Deciding when to inform your employer and coworkers about your condition is a decision only you can make. Telling your boss sooner rather than later has its advantages, especially if your symptoms start to get worse and begin to affect your performance. By making your boss aware of your condition, he or she can then work with you to accommodate your needs.

Many newly diagnosed people with Parkinson's avoid telling their employers and coworkers about their condition because they fear they will be unfairly treated. But the Americans with Disabilities Act (ADA) was created, in part, to keep employers from discriminating against people with disabilities or certain health conditions when they are hired, on the job or being fired. Every work setting is different. It is important that you feel comfortable with your choice.

Workplace Accommodations

By law, people with Parkinson's are protected against discrimination in employment practices. The ADA requires employers to make reasonable accommodations for employees, as long as they do not impose an "undue hardship" on the employer's business. A reasonable accommodation is defined as "any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions."

One source of information about the workplace is the Job Accommodation Network (JAN) — a free consulting service provided by the U.S.

Department of Labor. JAN works to increase the employability of people with disabilities by providing individualized worksite accommodation solutions; providing technical assistance regarding the ADA and other disability-related legislation; and educating callers about self-employment options. Contact JAN at ASKJAN.org/disabilities/Parkinson-s-Disease.cfm or 1-800-526-7234 for suggestions for accommodations under the ADA.

Adapted from Parkinson's Foundation Fact Sheet "Employment with Parkinson's Disease: Working It Out." Full Fact Sheet available at Parkinson.org/Employment.

APPENDIX C

How Can I Give Back?

"I began doing advocacy work for Parkinson's disease 2 years after I was diagnosed. I have been a Research Advocate with the Parkinson's Foundation for 11 years, served as a PPAC member for 3 years and I now also serve as an Aware in Care Ambassador. Though PD ended my career as a scientist, my association with Parkinson's Foundation opened a lot of new doors for me. I transitioned from a research scientist to a research advocate. Thank you PF!"

**GIRIJA MURALIDHAR, 61, SIXTEEN YEARS
AFTER DIAGNOSIS**



Advocacy can empower people living with Parkinson's. Community outreach can help others understand the disease and move them to also take action against PD. Donating to organizations that support PD care and research is another meaningful way to give back to the PD community. Becoming involved in clinical research studies and clinical trials contributes to the understanding of Parkinson's and improves treatment.

People with Parkinson's and their care partners can advocate at local and national levels for funding increases, prioritized research and improved PD education. You can also play a part in speeding improved treatments by applying to join the Foundation's Parkinson's Advocates in Research (PAIR) program. The cornerstone of the program is a national network of 300 Research Advocates who are working with scientists to help prioritize research, improve studies and influence stakeholders.

To learn more about how to get involved in fundraising, research and advocacy opportunities for people with PD, contact our Helpline at 1-800-4PD-INFO (473-4636) or visit www.parkinson.org.

APPENDIX D

Planning for the Future

Some people with PD express the desire to live in the present, not wanting to think too much about what the future may hold for their disease progression. Others can become preoccupied with what PD stage they are in, what symptoms to look out for, how fast the disease will progress, or what will happen to their family or lifestyle down the road. Try to maintain a balance between living in the present and planning for the future. There are many benefits to living mindfully and in the moment; but we cannot predict what the future holds. It is worthwhile to reflect on how we can possibly shape the future. Planning for it, as much as possible, can offer peace of mind and a better sense of control.

Build your support system. Reflect on whether or not your current support system – including partners, family, friends and where you now live – can continue to support your changing needs. If, over time, you require more assistance, or health issues arise for your primary care partner, are there people who are willing and able to help you in the way you might need or would you need to modify your situation? Ask yourself who you can turn to. Think about physical, logistical, financial, emotional and other types of help you may need, both in the near future and further down the road. Building your support system also means being open to assistance others offer you and recognizing times when you could use help, even with small tasks.

Budget your finances. Factor in the possibility of future care needs, including possible professional in-home care or a potential move to a long-term care community, such as assisted living. You may also benefit from budgeting for future medication costs, home modifications and adaptive equipment. Remember that Medicare will not cover all of your needs and plan accordingly.

Complete advance directives. Ensure the planning you need and want by taking steps to express your wishes to your loved ones. Care and estate planning include:

- Durable financial power of attorney – This document authorizes your designated attorney-in-fact, or agent, to manage your finances, taxes and legal matters if you are no longer able to make those decisions yourself.
- Healthcare power of attorney – This legal document permits a person of your choosing to make decisions about all aspects of your healthcare if you are unable to make them yourself.
- Living will – Valid in most, but not all, states, this legal document addresses your beliefs regarding certain end-of-life care interventions in case you are unable to express those desires when you need to.
- Medical orders – If you have strong beliefs around life-prolonging interventions, have a conversation with your neurologist or family doctor about what tools are available to help you express these wishes to your family and healthcare team.

ABOUT THE PARKINSON'S FOUNDATION

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community. A wealth of information about Parkinson's and about our activities and resources is available on our website, Parkinson.org.

YOUR FEEDBACK MATTERS!

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

ONLINE FORM: Parkinson.org/Feedback

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

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