

Updated
Summer
2021



If I Knew Then What I Know Now

The Michael J. Fox Foundation
Patient Council's Guide for People
Newly Diagnosed with Parkinson's



“My first thought was, ‘What the hell happened to me? What am I going to do?’ That took time to work through, but I found out that if I could accept what my situation was, and be honest about it, I could move forward. And my happiness grows in direct proportion to my acceptance.”

— Michael J. Fox, *diagnosed in 1991 at age 29*

FRONT COVER PHOTO:

Shyam Parikh, diagnosed in 2017 at age 72, and his wife, Nalini, in their West New York, NJ, home.

Dear Friend,

Whether you recently learned you have Parkinson's or have been living with the disease for years, you know how unsettling this diagnosis can be. Many remember the exact date they became, to their shock, part of the Parkinson's community. Some hear only, "You have Parkinson's disease" — everything else is a blur. In its short history, The Michael J. Fox Foundation has helped countless people and families process their diagnosis and move through their earliest days with the disease. As a member of the Foundation's staff and, before that, a Parkinson's doctor in private practice, I have witnessed the emotions and questions that arise, and I know it is a challenging moment. It is not unusual to feel overwhelmed and entirely uncertain about what to do next.

But here's the good news: You don't have to figure out everything all at once. Breathe, take one step at a time, and be kind to yourself. Your path will fall into place. One of the best first things you can do is connect with others who are living with the disease. They share your feelings and concerns, and they've found answers to many of the same questions you're asking for the first time.

In this guide, five members of The Michael J. Fox Foundation's Patient Council offer insights, wisdom and practical perspectives on everything from finding acceptance to navigating your doctor's appointments. (Read more about our authors on pages 22 to 26.)

Whether you were diagnosed last week or last year, I hope you'll find this guide informative and comforting. Lean on people who want to support you, including all of us at The Michael J. Fox Foundation and in the global Parkinson's community. We are here for you every step of the way.

All my best,



A stylized handwritten signature in black ink, appearing to read "R. Do" followed by a flourish.

Rachel Dolhun, MD
Senior Vice President, Medical Communications



Six Tips for Your First Year with Parkinson's (and Beyond!)



See a Parkinson's Specialist

If you haven't already done so, see a movement disorder specialist, a neurologist with additional training in Parkinson's and other movement disorders. Because these doctors have more experience with Parkinson's, they are best positioned to give a second opinion on your diagnosis or care, develop an individualized treatment plan and update you on research. Try to see an expert at the start of your journey and at least once a year.



Learn about Parkinson's

Knowing the facts about Parkinson's can help you understand the disease and make informed decisions about your care. But too much information can be overwhelming and even misleading. Ask your doctor and other people with Parkinson's for credible resources to help you learn more about the disease and your symptoms.



Build a Support System

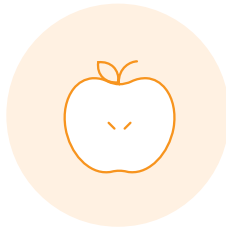
Know that you're not alone in Parkinson's and that there are many places to turn for help. Support means different things to different people, and it often changes throughout life with Parkinson's. A lot of people find support by talking with their spouse or a close family member or friend. And many also find it helpful to connect with others through Parkinson's support groups, online forums or even exercise classes.

Editor's note: Throughout this book, we've abbreviated "Parkinson's disease" as "PD" for the sake of brevity and simplicity.



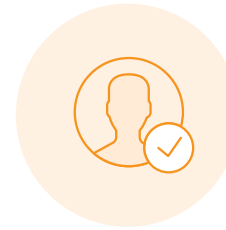
Exercise Regularly

Exercise can lessen movement and non-movement symptoms, such as depression and anxiety, which are common in Parkinson's and can increase around the time of diagnosis. Any type of exercise is beneficial, so find something you enjoy and will do regularly. Your doctor or a physical therapist can help you create the best plan for your interests and needs.



Eat a Healthy, Balanced Diet

There's no one specific diet for Parkinson's. But a nutritious diet that's high in fruits, vegetables and whole, unprocessed foods is good for your body and brain. Talk to your doctor or a dietitian to craft a diet that helps you manage your Parkinson's symptoms and feel energized and healthy.



Participate in Research

Too many people with Parkinson's regret not participating in research studies early on in their disease course, a stage of disease of particular value to researchers working toward cures. Taking an active role in such studies can be a way to take control when you may feel like much is out of your hands. There are many ways to get involved. You can participate in research, which often needs volunteers who are recently diagnosed and may not yet be taking medication. Or, you can raise research funds, serve on patient advisory committees or advocate for Parkinson's research policies.

For more information and resources visit michaeljfox.org.

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Bret Parker



Should I Get a Second Opinion?

When I first heard the words “I think you have Parkinson’s disease (PD),” I thought the neurologist was completely wrong. I was 27 years old, expecting my first child, and just starting my career as a family physician. It was overwhelming, of course, and I was pretty much in shock. I didn’t believe that the intermittent tremor in my pinky could possibly be Parkinson’s. I had expected a reassuring answer so that I could cross this annoying tremor off my to-do list and get back to my own patients and my busy life.

The details may differ, but the story is similar for many of us — you go into the doctor’s office with a myriad of non-specific symptoms, your doctor does a variety of seemingly simple exams, and you are given a diagnosis of Parkinson’s. This diagnosis is based only on what your physician sees during their exam and hears from you regarding your symptoms, because there is no blood test or brain scan.

Because of how Parkinson’s is diagnosed as well as questions or doubts that may surface, many people wonder whether they should get a second opinion. When I was not completely confident in my initial neurologist’s assessment, I asked for a referral to a movement disorder specialist (an expert Parkinson’s doctor), who unfortunately agreed I had PD. There is no harm in getting a second opinion, especially if you have not seen a movement disorder specialist, you have concerns about your diagnosis, or you simply want another perspective.


— SM



How Parkinson’s Is Diagnosed

To diagnose Parkinson’s, doctors rely on your medical history and physical examination. (That is why it’s beneficial, if possible, to see a movement disorder specialist, who has extensive knowledge and experience in PD.) There currently is no lab test or brain imaging scan that can, on its own, diagnose Parkinson’s. Doctors sometimes order these tests to exclude other conditions that can look like PD. And scientists are working diligently to validate a test to diagnose and measure PD — a biomarker — which would enhance research and care.

The Michael J. Fox Foundation’s landmark study, the Parkinson’s Progression Markers Initiative, is a large-scale collaborative effort to deepen understanding of Parkinson’s and find biomarkers. Learn more at michaeljfox.org/ppmi.

 Look for the fox throughout this publication for insights from The Michael J. Fox Foundation.



Are My Children Going to Get Parkinson's?

Not necessarily. Having a first-degree relative (such as a parent or sibling) with PD does slightly increase risk, but does not guarantee a future diagnosis. And it does not mean you carry a genetic mutation linked to Parkinson's (GBA, LRRK2, PRKN, SNCA and others) or, if you do, that you passed it on to your children. And many who carry a genetic mutation never go on to get Parkinson's. Researchers believe that the disease is caused by a combination of factors including genetics, environmental factors (such as head trauma and exposure to pesticides) and advancing age. Describing why he chooses to participate in clinical research, MJFF Board member Ofer Nemirovsky, diagnosed with PD at age 56, says, "Part of it is for me: I don't want to have Parkinson's if I don't have to. But part of it also is for my kids. I firmly believe that by the time they are of an age where they might develop Parkinson's, the disease will be gone."

How Did I Get Parkinson's Disease?

My journey to diagnosis took five years. I dealt with various symptoms — tremors, balance issues, slow walking and depressed mood — that all came and went. So, I dismissed them. The doctors I consulted with did, too.

When, at 42 years old, I was diagnosed, it was almost a relief to have an answer. But that answer quickly brought more questions and that relief soon turned to worry. No one else in my family had Parkinson's. So how did I get it? Was it in my genes? Would my girls get it? Did I do something to bring this on?

I spent a lot of time researching potential causes and talking to my doctor about what could have caused my Parkinson's. Yet eventually, like most people, I came to the conclusion that, right now, I couldn't know the exact cause.

So rather than continuing to look for "how," I started looking for the "why." Not in a "why me?" sort of way (I did have those feelings but tried not to wallow in them) — more "why is this part of my life and what can I do with it?" That led me to dive head-first into getting the best medical care possible; staying active physically and mentally; and advocating for PD awareness, education and policy. I found that the more I focused on helping others and making all of our lives better, the less bothersome my symptoms seemed.

— IR

What's Going to Happen to Me?

When I was diagnosed at age 38 and saw patients in the doctor's office whose disease was further along than mine, I worried that my condition would deteriorate quickly. That was over a decade ago and I'm still doing reasonably well, working full time, spending time with friends and family, and running/walking marathons. (It was a particular point of pride, 11 years into my PD journey, to complete the World Marathon Challenge — seven marathons in seven days on seven continents — to raise money for Parkinson's research.)

Just as we are unique and varied individuals, every person with Parkinson's travels their own path with varying symptoms and different timetables. While Parkinson's symptoms do worsen over time, how and to what degree is different for each person. It may be years or decades from diagnosis until you experience activity-impeding or life-altering symptoms.

For me, there are times when my symptoms, such as foot cramps, are quite pronounced and literally stop me in my tracks. But there are other times when my medicine works well and my symptoms are barely noticeable. The unpredictability can be frustrating, but the bottom line is that things are not as bad as I had feared.

— BP



Will I Die from Parkinson's Disease?

It's natural, fair and common to wonder what Parkinson's disease means for your future and how it will affect your life. Many people work for years, or even decades, after their diagnosis, and some are surprised to find themselves more active and engaged than they were prior. It is commonly said that people die with, not from, Parkinson's. Yet it is true that for some with advancing disease, worsening symptoms can bring on complications, such as swallowing problems or immobility, that can contribute to poor health outcomes. The good news is that unprecedented momentum is giving us more treatment options to address every aspect of PD, helping more patients live well for longer with the disease. (Since 2014, 17 new Parkinson's treatments have been approved by the U.S. Food and Drug Administration — a major acceleration from just a decade ago.) The Michael J. Fox Foundation exists to support and speed this momentum until patients have treatments equal to every symptom and, ultimately, a cure.

Managing Emotions in the First Days

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Israel Robledo

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Anna Cohn Donnelly



Will I Ever Fully Accept My Diagnosis?

Coming to terms with my Parkinson's was not something that happened overnight. I had to tell myself many times that my diagnosis was here, it was happening now, and it was unavoidable. And that I needed to start planning for what would come next. "Acceptance" can mean different things for each of us. There's not an acceptance light switch that you turn on and one day everything is manageable. It happens gradually, a little more each day, through support from your family, your network of friends and for some like me, even your work.

The most difficult part was hearing conflicting reactions from the closest people around me when I disclosed my diagnosis. Sometimes I would get, "I'm so sorry, I didn't know you were sick." This was frustrating because I wasn't "sick." I didn't feel feeble or in need of sympathy. Other times I would hear: "You look great, so you must be OK!" This didn't work either: I had just been diagnosed with an incurable disease — didn't they have any concern for me? These ups and downs were especially difficult as I tried to sort through my own internal battle of what it meant to have Parkinson's.

With time, I began to slowly find my own version of accepting Parkinson's. It sounds cliché, but I discovered that the less I thought of only myself, the better I felt, and the more I could help others — a virtuous cycle that still holds true today. Of course, it isn't perfect. I still grapple with balancing my emotions. But coming to terms ultimately freed me to live a life of service, which I value immensely.

So yes, you can come to acceptance and you will get back on an even keel after your diagnosis! Give yourself time, space and grace to fully move through your emotions. Take each day as it comes — knowing that some days will always be rougher than others. But that was true before you had Parkinson's, too. Find something that inspires you. And always keep hope on the horizon.

— IR

There's not an acceptance light switch that you turn on and one day everything is manageable.



Does Stress Make PD Symptoms Worse?

I wish Parkinson's came with a "Get Out of Stress Free" card. Unfortunately, just as in my life before my diagnosis, there's no shortage of stressful situations. They find me through my work and volunteer activities, the needs of family members, big events like the holidays and even the news. But here's the kicker: My symptoms, particularly my tremors, are more pronounced when my life is filled with stress. And that stresses me out even more!

I find that simply talking with others living with PD about how to manage stress is a stress reducer. And through those conversations, I've learned that no, it's not just me — stress really can make Parkinson's feel worse. But the good news is, we have the power to control our quality of life, at least in this regard.

So how do I manage my stress? Here is what's worked for me: I've slowed down. I try not to overcommit to any plans. I've gotten more comfortable saying "no" when I need to (a big change from my younger days). Exercise (of both body and mind) also helps. I take yoga classes, which creates a quiet, restful space in my life. Others have told me they find value in practicing meditation or mindfulness, learning breathing techniques or tai chi, or pursuing artistic endeavors such as painting or drawing.

Like every part of our experience with Parkinson's, how we manage our stress is highly individual. All that matters is finding what works for you, and then doing it.

There Are Reasons to Be Hopeful

I tend to be a "glass half-full" person, seeking out the positive in most situations, but that wasn't always the case. When I learned I had Parkinson's in 2010, at first I saw only the negative. I didn't know much about PD before my diagnosis, and it was frustrating to learn that there were still many fundamental questions about the disease remaining to be answered.

In the years since my diagnosis, I have seen remarkable changes in the Parkinson's landscape. There has been a veritable explosion of research to help all of us living with PD better manage our symptoms and live healthy, productive lives. I have watched as resources from scientists, health care professionals and support groups have become more plentiful, and more accessible. And awareness of the disease has grown, too, both among those of us with the disease and the general public. Today, there's an outpouring of interest in Parkinson's research from pharmaceutical companies, and increasing funding for basic research that forms the backbone of all drug development.

This tide of change has been driven, in large part, by the engagement and optimism of those of us who live with Parkinson's. As more patients make the decision to participate in research studies, we'll continue to make faster progress toward better treatments and a cure. So take heart. The future of Parkinson's research and care looks bright.

— ACD (*both essays*)



Taking Control of Parkinson's Disease

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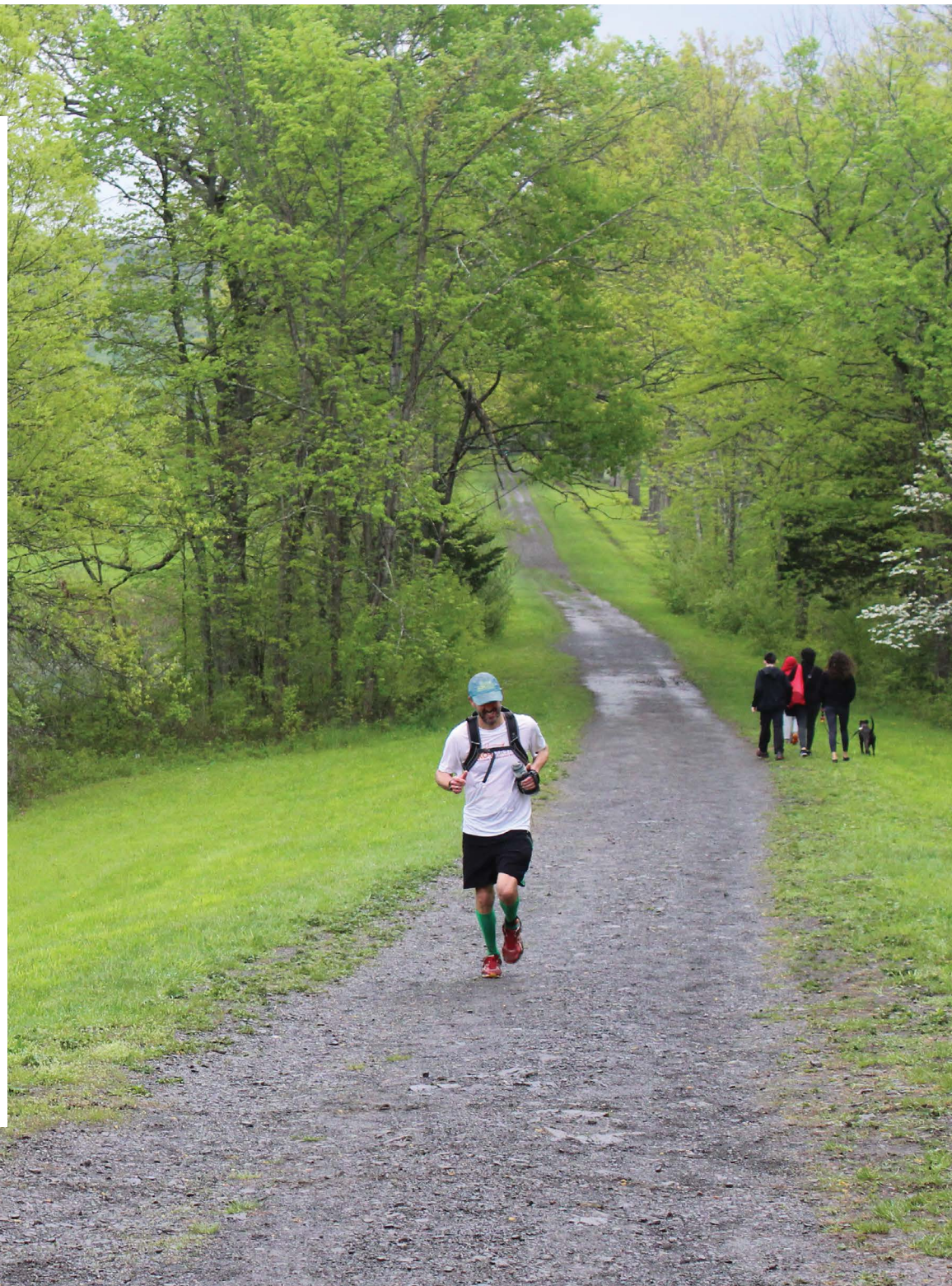
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Bret Parker and Israel Robledo



Whose Advice Should I Listen To?

As medical professionals, we came into our lives with Parkinson's already having some experience recognizing and managing symptoms and medication side effects. But a medical education is not a prerequisite to becoming an informed patient. And in any journey with Parkinson's disease, knowledge is power.

As someone living with a disease, you may be surprised to discover that you are surrounded by professional advice-givers — only some of whom are qualified to guide you. You can find yourself inundated with a vast amount of information — from your physician, allied health care professionals, members of the patient community and well-meaning family and friends. And searching the internet can be genuinely hazardous to your health. The key is to know how to sift through the material and incorporate only what is relevant and beneficial to you. It's the original “take what works and leave the rest.”

So where do you start? First, identify a list of reputable sources for information. It's ok if it starts small — you'll probably add to it over time. Ask your physician for organizations or websites she trusts and recommends. (The authors of this guide uniformly recommend michaeljfox.org as an excellent and credible source of information and community. For a list of additional resources, see page 20.)

Another wellspring of information and tips is patients themselves. You can learn a great deal from those who are living a similar life experience. I have found that the more practical solutions for some of the challenges I face daily have come from other people living with Parkinson's. Reading this guide is a good start. A support group is another option.

It can take time to get up the courage to start looking for a support group. It's easy to avoid an experience that seems like it will consist mainly of listening to people complaining. But if you go, you may find yourself connecting with a group of people who understand what you're going through and can provide invaluable hope and insights.

There are different types of support available, including online and face-to-face groups. You should choose one that works best for you. And if you have a hard time finding a local group, start your own! That's what one of the authors of this essay did — her group is called Shaker's Anonymous. It brings together people living with Parkinson's, care partners and others to support and encourage each other. During the first part of monthly meetings, speakers talk to the group about important topics, such as meditation and yoga. During the second half, we break into groups to provide mutual support.

MJFF recently launched the Parkinson's Buddy Network, an online support community for creating connections and conversations on topics from taking control of PD and medications to participating in clinical trials. It's open to people living with the disease and loved ones. You can join at parkinsonsbuddynetwork.org.

In our experience, groups can help you develop knowledge, strength and hope with the disease. Members share the sentiment that we didn't have the choice to get a Parkinson's diagnosis, but we do choose how we deal with it, both together and alone. The bond created may be stronger than expected. In time, your only regret may be not looking for a support group sooner.

— LH and SM



Medication and Treatment Early in PD

Currently available Parkinson's therapies aim to ease symptoms, keep you active and improve quality of life. There is no one-size-fits-all approach to Parkinson's care. Early in disease course, you may not feel you need medication. Many people wait to start using Parkinson's medicines until symptoms begin to interfere with activities they want or need to do, such as exercise, travel, or visits with friends or grandkids. Weigh medications' pros and cons with your doctor to make the best decision for you. To read more about PD treatments, visit michaeljfox.org/medications.

How Can I Manage My Symptoms?

Much like our body needs exercise, our brain needs to be challenged. There are many ways to work toward optimizing brain health. Research shows that following a Mediterranean diet rich in plant-based foods is good for overall health, so I frequently base my meals on vegetables, fruits, lean protein, legumes, beans and whole grains. I do my best to eat organic foods, try to minimize pesticide exposure and limit sugar intake. I'm also mindful of staying hydrated, which can help with constipation and low blood pressure. It's important to ask your doctor about your diet and any restrictions and the timing of protein intake relative to when you take your medication.

Exercise seems to have specific benefits for people with PD. It can help with balance, mood, mobility, tremor, thinking and memory, and alleviate constipation. When I exercise, I immediately feel the difference both physically and cognitively. There are many programs with professionals specially trained to work with people with Parkinson's, like the Rock Steady Boxing and Dance for Parkinson's programs. Lots of people with PD find benefit in yoga and cycling, too. Joining an exercise class or activity that you enjoy will help you stick to it. Ask your doctor before starting an exercise program or routine to make sure it's at a safe level for you.

Make sure to get enough sleep, reduce stress, exercise, maintain a healthy diet and remain socially active. You can also do crossword puzzles, learn a new language or take up a new hobby.

Of all the symptoms of the disease, problems with cognition are the most unsettling for many. Some individuals may have no notable changes, but others may notice changes in thinking or memory. While the disease itself can cause cognitive changes, other factors that can cause cognitive issues are certain symptoms, such as mood or sleep changes, as well as some prescription and over-the-counter medications. It's important to be open with your doctor about any changes that you notice.

— LH

Making the Most out of My Doctor's Appointments

Whether it's a friend, loved one, family member or care partner, having another person at your appointment helps in so many ways. We both were resistant at first to have our wives join us — we didn't want to concern them or be a burden on their already hectic schedules. But we've come to realize that it's important to have a more objective person in the room. We find that our wives help us get the right questions asked. (Israel always seemed to remember something specific that was important on the drive back home, when it was too late.) Bret's wife, Katharine, takes notes and answers questions about things he may not see, such as sleeping patterns or a subtle new symptom. It's also a good opportunity for them to ask their own questions since, after all, we are going through this together.

Bringing someone else to the appointment has prompted us to plan ahead. In preparing for each appointment, we think of concerns and questions that we want to discuss. For Israel, the best, tried-and-true method is to put these on an index card (including his own and his wife Chris's questions) and leave space to write the doctor's answers. After the physical exam, the index card goes on the table to make sure everything is addressed before finishing the visit. The index card keeps us focused and doesn't take any longer than a regularly scheduled visit. The movement disorder specialist has even started asking, "What does Chris want me to know?"

— BP and IR



Care Partners Can Take Control Too

Caring for a person with a chronic illness can be emotionally demanding. Caring for yourself is just as important, if not more so, as caring for your loved one. Eat healthfully, get plenty of rest and make it a point to exercise. But most importantly, don't stop living! Although your life has changed, you still have one. Preserving as much of your life as it was before the diagnosis will enhance the overall quality of life for you and your loved one. Ask for help. No one is able to take care of another person 24 hours a day, seven days a week. Put together a list of friends and family members you trust and can call upon to relieve you for a few hours or in case of an emergency. If the financial means are available, seek outside professional help for in-home assistance. Get more advice for care partners at michaeljfox.org.

— Lonnie Ali, MJFF Founders' Council



Bill Rasmussen: Embrace Early Engagement

I've told the story about getting fired from the New England Whalers and founding ESPN countless times. To athletes. To college students. But since my diagnosis with PD in 2014, the story I share is much different. Whatever the story may be, I share my truth in the hopes of helping just one person. I'm an optimist. And that's my measure of success. Life isn't about the obstacles you may encounter, it's how you figure out a way around them. I think of my Parkinson's this way. My diagnosis was a relief. Ultimately, I thought it was better to know my disease, to give it a name and to meet the challenge head on.

I remember telling my friend Mike Soltys, a vice president at ESPN (I hired him years earlier as an intern!), well, maybe we can help somebody — Mike, what do you think? And so he assigned a writer, we talked about it for a few weeks and got it together, and he said, you know, if just one person is helped, that'd be great. And I heard from people all over the world. Believe it or not, I had responses from Denmark. I guess because Rasmussen is the biggest name in Denmark. There are more Rasmussens there than anywhere else.

Everybody had their own approach to how they were going to take care of it. I can't say anybody is happy with Parkinson's, but many feel at peace with where they are, and they're determined to make the best of it. They all emphasize exercise. One way or another, everybody has a different regimen. That doesn't mean my way is better than your way or Joseph's is better than Clyde's, but keep moving, keep walking, keep exercising,

stretching. I played baseball and softball for a number of years and I was a catcher, which is really tough on the knees and the legs. When I can't get into the catcher's position, then I'll know my legs are really around the way out! But I think that's only because I exercise. Wake up, make the bed, exercise, eat breakfast. I go for a walk and that's fine. I don't have a job that I have to go to. Fortunately, I'm too old! Nobody will have me at my age. I make doctor appointments, stay connected to friends and exercise on my daily walks. Reframing life's challenges also has been a constant.

The obstacles in my life won't stop — and I won't let them stop me. I've fallen a few times in recent years. My doctor and I made workarounds to address this and I accept it for what it is. But other than that, everything is good. I still grumble at my computer. I still enjoy meeting new people. And I continue to be grateful that I can share my story. I hope my life story can help more people — even just one more person.

MJFF Patient Council member Bill Rasmussen, 88, diagnosed with Parkinson's disease in 2014, is using his inspirational life story and good humor to encourage others with PD to stay active and get involved in the community — and to embrace participation in research to speed better treatments and a cure.



The Foundation is grateful to ESPN for making our partnership with Bill Rasmussen possible.

A Golden Opportunity to Speed the Cure: Your First Year with Parkinson's

The first few months and years following a Parkinson's disease (PD) diagnosis can be overwhelming. Few people think about participating in clinical trials during this time. But people in this fleeting window are in a unique position to contribute to research and help scientists capture the full continuum of Parkinson's. **Below are six key facts.**

1 Studying the earliest stages of PD is critical to speeding a cure

Especially before you start Parkinson's medication, scientists need your partnership to understand, measure, prevent, slow and stop the disease. Your participation in research can help researchers gain tremendous insights into early disease processes that may be our best hope to slow or stop the progression of PD (something no currently available treatment can do).

4 Your safety is top priority

Safeguards are in place to minimize risk in research trials. Researchers must have all study plans and materials approved by an outside committee of experts and must monitor for and report any undesirable changes in a person's health throughout the course of the research.

2 Many patients regret missing this window of opportunity

The Michael J. Fox Foundation regularly hears from people with PD who did not come to understand soon enough that their early participation in research held particular value to the development of cures. Many wish they had asked their doctor for information on research participation, or learned sooner about the Foundation's trial finder tool (michaeljfox.org/trial-finder) that matches individuals to studies that need them.

5 There is a study (or several) for you

Interested in participating in online research? Join Fox Insight, MJFF's online clinical study where people with and without Parkinson's share information that could transform the search for better treatments. Register at foxinsight.org.

3 Participation brings risks and benefits

Not all studies test a new drug; many collect data and samples to better understand the biology of PD. Some test exercise, physiotherapy or other non-invasive treatments. While some risks are inherent in research, participation may also bring benefits. Some people say they gain a sense of control over their disease. Research could also offer more time with Parkinson's experts and early access to emerging treatments.

6 Parkinson's research needs you now

The Michael J. Fox Foundation's landmark study, the Parkinson's Progression Markers Initiative, could change the way PD is diagnosed, managed and treated. The study is now recruiting people diagnosed with PD in the past two years and family members of people with PD. Get started at michaeljfox.org/ppmi.

How and When Will I Know I'm Ready to Share My Diagnosis?

A conversation with
Soania Mathur and
Bret Parker, Patient
Council Co-Chairs



Soania Mathur: Bret, I'm looking forward to discussing this topic with you.

Bret Parker: Same here, Soania. I feel like our stories have a lot in common and I hope they'll resonate with readers.

SM: For well over a decade, I chose to not disclose my diagnosis to anyone, except for a very select few.

BP: Yes. Deciding who, when and how to tell people about my Parkinson's was one of the biggest early issues that challenged me.

SM: In my case, some of it was my own denial and fear of what people would think, but it was mainly dreading the thought of being viewed as less capable than others, labeled as "sick" and treated differently due to others' misconceptions.

BP: As a father of two young boys, working at a demanding job, I didn't want people to know. I was only 38 and my symptoms were so minor that no one noticed at first. I told my parents, my wife and a few close friends, but no one else. I was particularly concerned about people at work finding out because I didn't want it to impact other people's decisions about my career.

About Young-onset Parkinson's Disease

Young-onset Parkinson's disease (YOPD) generally is defined as Parkinson's diagnosed at age 50 or younger. While treatments are the same no matter when PD is diagnosed, younger people may experience the disease differently. People with YOPD may have a longer journey to diagnosis, sometimes seeing multiple doctors and undergoing several tests before reaching a correct conclusion. When younger people and their clinicians are not expecting Parkinson's disease (PD), the diagnosis may be missed or delayed. It's not uncommon for arm or shoulder stiffness to be attributed to arthritis or sports injuries before Parkinson's is eventually diagnosed. Although everyone with Parkinson's wonders what the years ahead hold, this may be top of mind in those who have a longer future with PD. Concerns often center on the potential implications of the disease on personal, family and professional desires and responsibilities, including impact on finances, family planning, parenting, relationships and marriage. You'll find a wide array of resources for learning about and coping with YOPD at michaeljfox.org/yopd.

SM: I felt myself withdrawing, starting to isolate because the time I would have to spend fixating on hiding my symptoms outweighed any pleasure I would feel being there. The secret made it difficult for family and friends to get close.

BP: As time went on, and the disease progressed and became more visible, hiding was stressful. And then telling close friends and family, which I did one at a time, was emotional and almost as difficult as hiding it. So I went big. I wrote a blog post "outing" myself on Forbes and told everyone to read it. It proved cathartic. It allowed me to take a small bit of control over the disease.

SM: I didn't go quite as big. But despite my hesitation, I began to tell my friends. Did everyone react the way I had hoped? No, of course not. There were a few who seemed more devastated than I had ever been. Others were overwhelmed by it all and chose simply not to acknowledge the situation. But mainly there was unconditional support. The "pity party" I had feared never took place.

BP: My friends were all ready to support me and work colleagues couldn't have been more understanding.

SM: As a physician, disclosing my diagnosis to my patients and colleagues was a similar experience. But there are many points to consider when making that decision — the nature of your job, workplace safety, your disability insurance status, and your employer's policy or past actions regarding chronic illness in the workplace.

BP: Right. It depends on your relationship with your boss and your employer, but telling them can sometimes make it easier to ask for an accommodation and prevents them assuming something is wrong with your work performance when it's actually health-related. And if you aren't sure how the law protects you, it's worth contacting an attorney to understand your options.

SM: I guess when all is said and done, disclosure is a very personal milestone and it's different for everyone. The timing may feel right when you've come to some personal level of acceptance about your situation, or you may want to reach out sooner in order to get some extra support while you get your head around the diagnosis.

BP: I totally agree. It's your information to share as you like, and there are different reasons, times and circumstances when you may want to keep it to yourself and others when it makes sense to share.



Resources

Learning about Parkinson's disease can help you make informed decisions on your disease journey. The Michael J. Fox Foundation offers a variety of resources covering many aspects of life with Parkinson's at michaeljfox.org.

Parkinson's 360

A candid and relatable multimedia suite of materials for patients and families living with Parkinson's that walks through the different symptoms as well as the emotional and social changes that may arise at different points in the PD journey. Learn more at michaeljfox.org/PD360.

Navigating Clinical Trials

A comprehensive guide and video suite for patients and their families offers information and first-person narrative to fill knowledge gaps and demystify clinical studies. Discover more at michaeljfox.org/participate.

Educational Guides

In easy-to-read guides, movement disorder specialist and MJFF's Senior Vice President of Medical Communications, Rachel Dolhun, MD and other experts provide practical tips and real-world advice for navigating different facets of life with Parkinson's disease. Download the free guides at michaeljfox.org/guides.

Ask the MD

Movement disorder specialist and Senior Vice President of MJFF Medical Communications, Rachel Dolhun, MD, translates Parkinson's care and research into blogs, videos and downloadable guides. Learn more at michaeljfox.org/Ask-the-MD.

Webinars

In our Third Thursdays Webinars every month, experts discuss various aspects of living with PD and the Foundation's work to speed medical breakthroughs. View webinars live and on-demand at michaeljfox.org/webinars.

Podcasts

Scientists, doctors and people living with Parkinson's discuss different aspects of life with the disease as well as research toward treatment breakthroughs. Listen at michaeljfox.org/podcasts.

Ask the PhD

In a video series, scientists discuss the latest from the Foundation's research portfolio and new findings that advance understanding, measurement and treatment of Parkinson's. Watch at michaeljfox.org.

Fox Trial Finder

Fox Trial Finder is an online clinical study matching tool designed to instantly connect willing volunteers with studies. Join a study today at michaeljfox.org/trial-finder.

Parkinson's Progression Markers Initiative (PPMI)

The power of the Parkinson's community is leading to new findings on symptoms and biology through MJFF's landmark clinical study. Join PPMI and contribute information that may help us understand who is at risk for Parkinson's, who ultimately gets the disease, who does not, and why. Learn more at michaeljfox.org/ppmi.



Meet the Authors



The authors of this guide are members of The Michael J. Fox Foundation's Patient Council. Established in March 2009, the Patient Council serves as a formal channel for the Foundation to solicit input from Parkinson's patients and the broader Parkinson's community. The Council advises the Foundation on programmatic fronts including (but not limited to) strategies to best convey patient priorities to the research community and its funders; creating educational content most relevant to patients; emphasizing patients' role in MJFF's mission to find a cure; developing novel ways to conduct research and mechanisms for impact assessment.

DIAGNOSED IN

2010

LOCATION

Winnetka,
Illinois



Anna Cohn Donnelly, DPH

At the age of 65, Anna received her Parkinson's disease diagnosis. She holds a doctorate in public health and is a faculty member at the Kellogg School of Management, Northwestern University and the founding director of the Kellogg Board Fellows Program. She shares her expertise and passion for public health and well-being with various nonprofits, and wrote and illustrated *Steady as a Rock*, a book (available in English and Spanish) about the benefits of group exercise for people living with Parkinson's.

"I know that a Parkinson's diagnosis is shocking. It can take time to accept it. My advice for anyone newly diagnosed is to give yourself that time."

Lynn Hagerbrant, RN, BSN

Lynn was diagnosed with Parkinson's disease at age 54 and is a caregiver for her mother who was diagnosed at age 78. Lynn is a registered nurse with experience in cardiac and medical surgical critical care units and has worked for pharmaceutical companies as a teaching hospital representative. She is active in her community, serving on various boards, running a wellness program, Parkinson's Body and Mind, and co-leading a young-onset Parkinson's disease support and networking group, Shaker's Anonymous.

“Take a deep breath and realize you can live well with Parkinson's.”



DIAGNOSED IN
2010

LOCATION
Greenwich,
Connecticut

DIAGNOSED IN

1998

LOCATION

Ontario,
Canada



Soania Mathur, MD

Soania was diagnosed with young-onset Parkinson's disease at age 27. Twelve years later, she resigned from her practice as a family physician and began to focus on learning to thrive, not just survive, with Parkinson's. Passionate about helping patients take charge of their lives and live well with Parkinson's, Soania dedicates her time as a speaker, author, educator and Parkinson's advocate, serving on several boards in Canada, the U.S. and abroad.

“Recognize that you may not have a choice in your diagnosis, but how you face those challenges is yours to determine.”

Bret Parker, JD

Bret was diagnosed with young-onset Parkinson's disease at age 38, experiencing just a slight tremor in one hand. He kept his diagnosis relatively secret for five years, until he shared it all in a blog for everyone to read. Bret works full-time as executive director of the New York City Bar Association and is running toward a cure, completing marathons and participating in Team Fox, The Michael J. Fox Foundation's grassroots community fundraising program. Bret advocates for all patients to get involved and raise awareness for the need of increased patient participation in research.

“Try to exercise, spend time with supportive friends and family, and keep a good sense of humor.”



DIAGNOSED IN

2007

LOCATION

New York,
New York

DIAGNOSED IN

2007

LOCATION

Midland,
Texas



Israel Robledo

Israel was diagnosed with young-onset Parkinson's disease at age 42. He and his wife, Chris, have three daughters and three grandchildren. Israel is a special education teacher and an advocate for increased clinical trial participation and health-related quality of life issues that come with the disease. Dedicated to making a difference in the Parkinson's disease community, he has served on various councils, panels, boards and advisory committees, sharing patient priorities and insights into the lived aspects of the disease.

"Take time to come to terms with your diagnosis. Realize that life continues."

Credits

Thank you to the writers and reviewers living with Parkinson's disease who contributed their experiences and insights.

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The medical information contained in this guide is for general information purposes only. The Michael J. Fox Foundation for Parkinson's Research has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson's disease and any other medical condition be made in consultation with a physician or other qualified medical professional.

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**He doesn't
have Parkinson's.
But he can help
end it.**

Join the study
that could change
everything.



Parkinson's
Progression
Markers
Initiative

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments. Whether you have Parkinson's or care about someone who does, you can help.

Participate today at michaeljfox.org/ppmi.



About The Michael J. Fox Foundation for Parkinson's Research

In 2000, Michael J. Fox, an iconic actor, author, advocate and person living with Parkinson's, launched The Michael J. Fox Foundation for Parkinson's Research. Though he would not share the news with the public for seven years, Michael was diagnosed with young-onset Parkinson's disease in 1991 at age 29. Upon disclosing his condition in 1998, he committed himself to the campaign for increased Parkinson's research.

The Foundation is dedicated to finding a cure for Parkinson's disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. While we will never be satisfied until a cure is found, we take pride in our impact on the field of Parkinson's research. Since inception, the Foundation has quickly grown into the largest nonprofit funder of PD research worldwide, having funded over \$1 billion in research projects to date.

Download a free, digital version of this guide and browse additional resources at michaeljfox.org/newlydiagnosed.