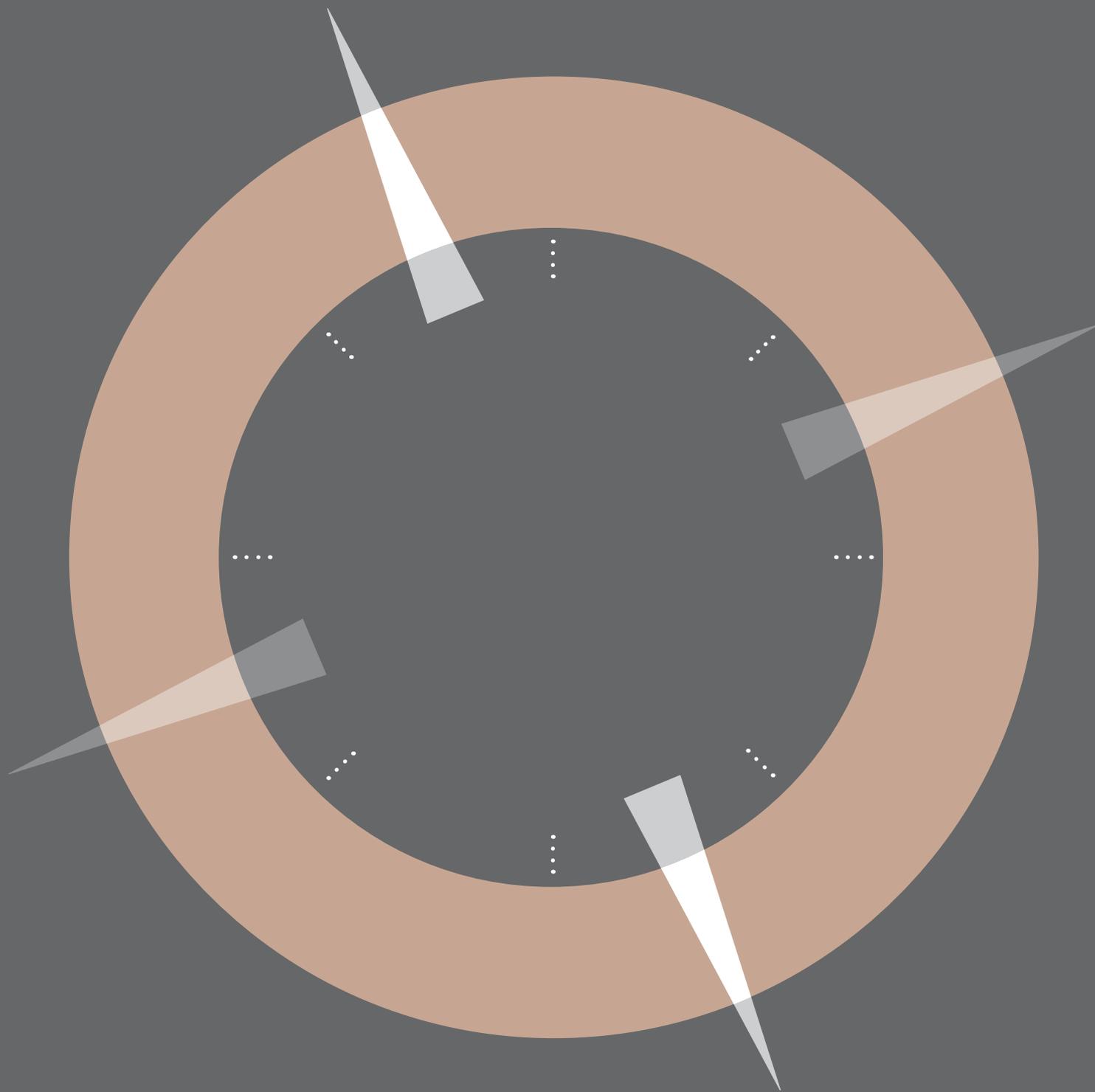


PARKINSON'S 360°



Real Talk
for Patients
and Families

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How (and How Not) to Use This Book

Every person diagnosed with Parkinson's disease (PD) embarks on a unique journey. No standard trajectory or path exists, and for many, this proves to be among the most challenging aspects of the disease. Since The Michael J. Fox Foundation's earliest days, we have received countless requests from people and families living with PD for candid, trustworthy and understandable information about what to expect as Parkinson's progresses — and for resources to chart the best course.

The goal of this book is to help you anticipate and navigate the clinical, emotional and social aspects of Parkinson's that often correlate with different phases of the disease. It's not intended to impose an artificial timeline upon the course of PD, nor to place a highly individualized disease into abstract categories. Each person's Parkinson's — the particular symptoms, impact and progression —

is distinct. There is no way to predict any one individual's path; you and your doctor will get a sense of how it unfolds with time. Recognizing the personalized nature of PD, though, we know that specific symptoms and transitions are more likely to arise at certain times as your life with Parkinson's moves forward. We want to give you the opportunity to face these potential pivot

points with extra assurance and identify with others' shared experiences.

We've set out to create a practical and appealing guide, one you and your loved ones will want to read and return to as you go through life with PD. Use it to spark conversations at home or in the doctor's office and refer to it for actionable tips.

As with any resource, take from it what resonates with you and move away from anything that feels overwhelming. Skim the chapters, digest a few pages at a time or scan the patient profiles. Don't read it cover to cover and imagine that a life with Parkinson's has been condensed into a short book. Put it down if it upsets you or you find yourself obsessing over the content, placing labels on your disease or fearing the worst about your Parkinson's. Remind yourself that you have your own version of Parkinson's. Some people prefer to concentrate on the "here and now" of their disease whereas others want to plan for a possible — not inevitable — road ahead. Whichever camp you fall into, this book contains information for you. Focus on what speaks to you.

This guide tries to lend structure to a highly variable disease by painting a broad picture around the most common experiences people tell us they encounter along the way. Remember, you won't have all the experiences in this book. Not everyone will reach the middle or later stages of PD or have the same degree of symptoms.

You'll find the information arranged in the following manner:

- » **Getting to Know Parkinson's Disease:** the emergence of symptoms, initial diagnosis and early years of living with disease.
- » **Paving a Path with Parkinson's Disease:** the progression of symptoms (to different degrees in different people); perhaps continued adjustment to life with PD; and, for some, when medication is started for

symptom management (although this can, of course, be earlier or later).

- » **Looking Ahead with Parkinson's Disease:** the advancing years of Parkinson's in which symptoms may be fairly significant and medication complications could be present. Not everyone with Parkinson's reaches this stage; even those who do won't experience everything that's discussed.

People living with PD today have reason for great optimism about their own futures with Parkinson's and that of the entire Parkinson's community. Research is rapidly moving forward, bringing us closer to a deeper understanding of the disease, concrete ways to diagnose and measure PD, better symptomatic therapies and ultimately, a cure. New symptomatic medications are making it through the drug development pipeline to pharmacy shelves. Therapies that could potentially modify the course of disease are in clinical trials. Parkinson's surgical procedures and devices are improving. Options are continually expanding to support you and your ability to live life with Parkinson's to the fullest at every step of your journey.

We hope this guide (and its accompanying website and video suite at michaeljfox.org/PD360) inspires you to get (or stay) actively involved in your care, engage in new ways with the PD community and live well with Parkinson's for many years to come.

HOW THIS BOOK WAS CREATED

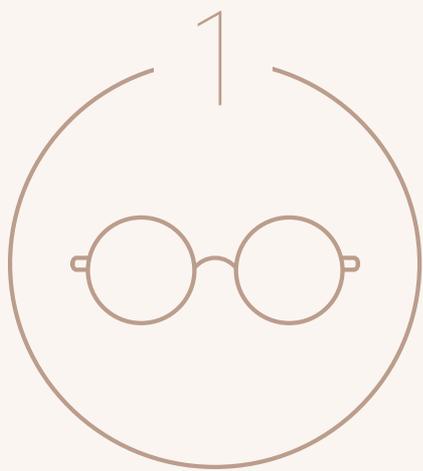
This book and the accompanying multimedia materials arose from conversations that repeatedly identified a need to broaden understanding of Parkinson's disease, including options for living well for those newly diagnosed or navigating new symptoms as the disease progresses, as well as those caring for a loved one with the disease. While we strive to capture the diversity of living with Parkinson's, we know we cannot represent every experience of this complex and varied condition.

Content development was led by Rachel Dolhun, MD, a movement disorder specialist, board-certified neurologist and vice president, medical communications at the Foundation.

We are grateful to Claire Henchcliffe, MD, D.Phil., of Weill Cornell Medicine for her expert medical review of the book and to Karen Jaffe, MD, and Soania Mathur, MD, members of the Foundation's Patient Council, for their evaluation of the book as people living with Parkinson's.

Special thanks to the four members of the Parkinson's community who lent their challenges, hopes, images and journeys with Parkinson's disease to this project: Lisette Ackerberg, Jimmy Choi, Michael S. Fitts and Richie Rothenberg.

Seven Tenets for Life with Parkinson's Disease



There is no “one size fits all” description of Parkinson's disease.

Your symptoms and progression are not like anyone else's. Monitor your own Parkinson's, educate yourself on the disease, and become the top expert on you.



Isolation can worsen symptoms.

You don't have to manage this disease on your own. A team-based approach (including a movement disorder specialist and allied care professionals) can help you stay physically and emotionally strong. Keep open lines of communication with loved ones and consider joining a support group.



Don't settle.

Parkinson's disease varies, and so do treatment options. Designing a regimen that feels comfortable and effective for you will take time and, likely, more than one try. Keep working with your doctor and care team until you get there. Make changes to address progression as needed.



Hone your news instinct.

The latest research is the latest hope, but in our 24/7 media environment, there's a learning curve to interpreting science news. Find experts you trust, seek out credible updates and commentary, and let go of the rest. Being news-savvy can help you maintain peace of mind.



Parkinson's is a non-linear disease.

You can have good days, weeks and months even during trying times. Exercising, eating well and staying involved with your social circle, community and activities you enjoy can have a major influence on your Parkinson's path.



Get engaged.

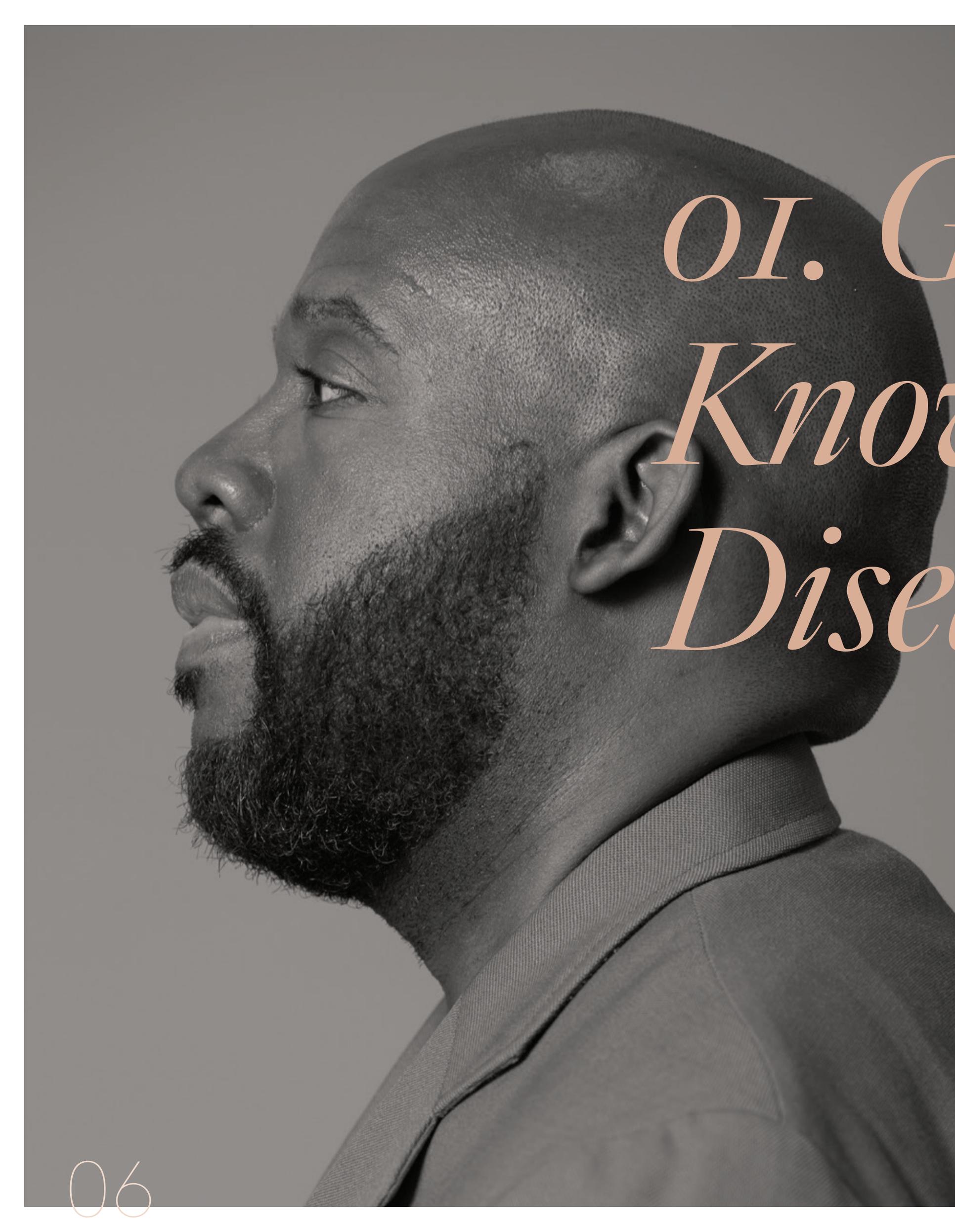
There are as many ways to contribute to better outcomes for yourself and others as there are people with Parkinson's. Participating in research studies or advocacy, raising funds, starting a blog or support group — however you choose to get involved — can give you a sense of control and help bring us all closer to a world without Parkinson's.



Be prepared.

Parkinson's diagnosis or not, we all face certain issues in our later years. Make sure your family understands your wishes for end-of-life care, and put your will and estate in order. Having challenging conversations at the beginning of your journey with Parkinson's can help lighten the burden as the disease advances.

“I feared Parkinson's most when I least understood it — the early days, months, and years after I was first diagnosed. It seems strange to say it, but I had to learn to respect Parkinson's disease.” — MICHAEL J. FOX



01. C
Know
Dise

Getting to Know Parkinson's Case

The diagnosis of Parkinson's is life-changing and takes time to process. Everyone works through this in his or her own way, and each approach will be different. Most people are able to keep living in much the same manner as prior to diagnosis — there is no need for sudden career changes or shifts in living arrangements. For many, however, now is an opportune time to plan for the possibility of adjustments in the workplace, at home and in relationships.

Michael S. Fitts
Diagnosed at age 38
Lives in Alabama

The Here and Now: Parkinson's-related Changes You May Notice in the Beginning

In early Parkinson's, symptoms come to attention and diagnosis is confirmed by a physician, on the basis of three cardinal motor symptoms:

- » Resting tremor: a rhythmic shaking that occurs in (typically) one finger, hand or arm when relaxed, and disappears when the appendage is being used
- » Rigidity: muscle stiffness detected on examination by a doctor
- » Bradykinesia: slowness of movement — may be experienced as reduced walking speed or arm swinging while walking, slowed rate of blinking or decreased facial expression

At the time of diagnosis, bradykinesia plus at least one of the first two symptoms (resting tremor or rigidity) is typically present on one side of the body. Although a resting tremor is the most common symptom at diagnosis, not everyone experiences it. Balance and walking problems — unsteadiness or changes in gait pattern and/or pace — may also be seen early on but, if they do occur, they are more likely to develop in later stages of disease. Dystonia, an involuntary muscle contraction that causes an abnormal sustained posture (such as inward turning of the foot), may be present at diagnosis, especially in younger people, but can occur throughout the course of disease as well.

The diagnosis of Parkinson's is based on a person's medical history and physical examination. No laboratory (blood, urine or spinal fluid) test or brain scan can confirm that a person has the disease. These exams often are done to exclude other conditions that can look like Parkinson's, but they alone cannot make the diagnosis. (Such tests will become possible with the discovery, still under pursuit by our Foundation and multiple research groups, of a so-called "biomarker" — an objective measurement that reveals the risk, presence or progression of disease. A good example of a biomarker is high blood pressure in heart disease.) With that said, in 2011 the U.S. Food and Drug Administration (FDA) approved a new type of brain imaging called DaTscan, which can help physicians evaluate movement disorders including Parkinson's disease. DaTscan can't diagnose Parkinson's on its own, but it can be a helpful adjunct to the clinician's diagnostic evaluation, particularly in differentiating essential tremor (an involuntary shaking of the hands, head or voice) from tremor due to Parkinson's disease or Parkinson's-related disorders.

Non-motor symptoms, which sometimes precede the onset of motor symptoms, also may support the diagnosis. Constipation, smell loss and certain sleep disorders are common, but other potential

non-motor symptoms include fatigue, memory or thinking problems, and mood disturbances, including depression. A few people won't experience any non-motor symptoms, but most encounter one or more over the course of their disease.

In the earliest years, symptoms (with the possible exception of fatigue or depression) may not significantly interfere with your work or physical or social activities. Because of this, and the fact that the available Parkinson's medications ease symptoms but don't alter the underlying disease process, many patients feel medications are optional for them during this time. Nonetheless, everyone experiences symptoms differently and when they impact quality of life — regardless of how long it's been since diagnosis (one day, one year or one decade) — medications should be considered. Don't save medication for a later date because you fear it may stop working or believe that the sooner you start, the sooner you'll have complications. While these concerns are understandable, not everyone experiences them and they are due to a complex mix of factors.

Since Parkinson's disease is unique to each individual, the rate and extent of its progression will vary from person to person.



"IT'S THE MIDDLE OF SUMMER.
WHY DID YOU ASK IF I'M COLD?"
"YOUR HAND IS SHAKING."

Michael S. Fitts looked down at his hand and back at his friend.
"Yeah, that's been doing that every now and then."

Michael's journey to diagnosis proved to be a frustrating one. He often sat at his computer, researching his mysterious symptoms. At first, his primary care physician shrugged off the concern of the otherwise healthy man in his late 30s. A referral to a neurologist finally led to his Parkinson's diagnosis.

Unlike many people with Parkinson's, Michael found medication necessary early on to manage his symptoms, but the right treatment proved elusive. A first therapy left him feeling "out of his mind." He experienced depression to the point that he was

unable to get out of bed for work each morning. He worried about becoming a burden to family.

He found a support group, but at first that was a tough fit too. He sat in his first meeting feeling like the odd one out, the only patient without white hair and the only African American. But he kept attending, and now he credits the group — along with his church and family — with helping him stay engaged with favorite hobbies, such as photography, and forge connections within the Parkinson's community. Now he has made it his personal mission to introduce Parkinson's resources to people of color who often go undiagnosed or undertreated.

WATCH MORE OF MICHAEL'S STORY AT
[MICHAELJFOX.ORG/PD360](https://michaeljfox.org/pd360).

Emotional and Social Aspects: What People with Parkinson's Say It Feels Like Early On

In many ways, the emotional aspects of receiving a Parkinson's diagnosis may be more profound than the earliest clinical symptoms, which typically are highly manageable.

Prior to diagnosis, uncertainty and anxiety are common. Symptoms may be attributed to normal aging or other medical conditions, such as arthritis or a sports or overuse injury. During this time, you might have been hiding symptoms and concerns from family and friends so they wouldn't worry. Learning that in fact you have a chronic, progressive disease can feel abrupt, if not surreal.

» For some, the diagnosis — having an explanation for their symptoms — brings a sense of relief. Others experience shock and disbelief. Those who are younger or lack a family history of PD may have more prominent denial and doubt responses. People who have maintained healthy lifestyles may wonder how Parkinson's is even possible when they "did everything right."

» Anxiety about unexplained symptoms can transform into worry about what a future with PD looks like. Feelings of depression may arise in reaction to diagnosis, but these also can be clinical symptoms of Parkinson's.

Depression is treatable but can be hard to recognize when you're going through it. Pay attention to what you hear from your family and friends — they may see changes in your mood or behavior before you do.

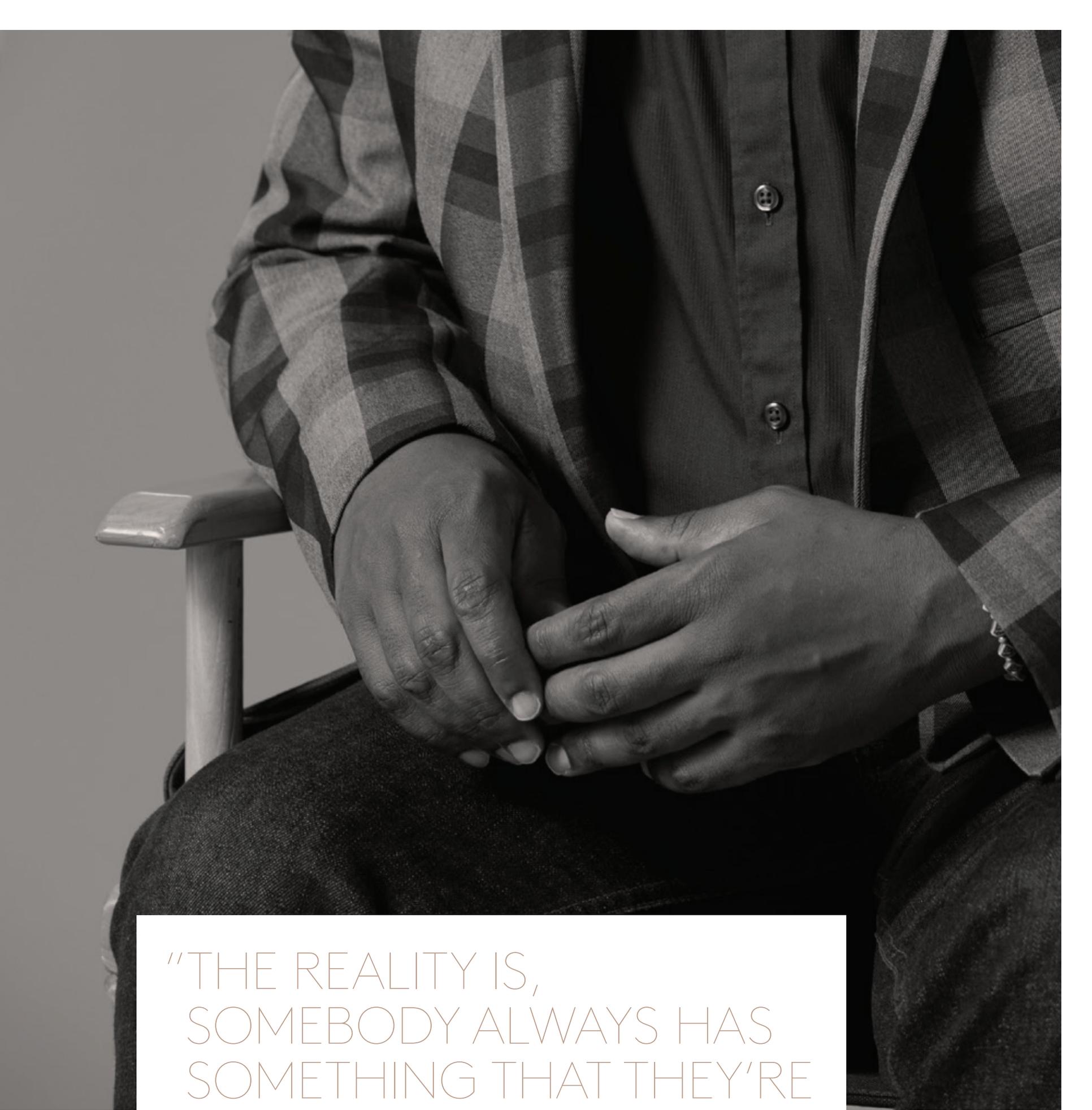
» Many people report feeling a sense of loss — a loss of control, and a mourning for what the future could have been — dreams, aspirations and events yet to come. At the same time, they may withdraw, either purposely or unintentionally, from social activities and interactions.

Most people probably go through a combination of feelings and responses. Adjusting to and accepting a Parkinson's diagnosis can feel overwhelming. But it is entirely reasonable to expect many of the years ahead to be as happy and productive as what came before. As patient authors of an early Michael J. Fox Foundation guide for the newly diagnosed wrote: "The initial reactions to diagnosis are stepping stones on the way to acceptance. When acceptance is reached,

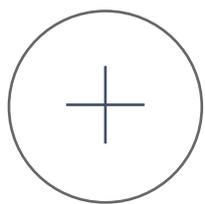
many look back at the period after diagnosis and realize that they were living in fear of a tragic future that never materialized."

At this stage you also may grapple with decisions about disclosure — how, when and whom to tell about the diagnosis. If you are undecided about sharing your Parkinson's diagnosis, consider outlining a strategy in advance. Having a solid plan in place for deciding whether and when to disclose, delivering your news and navigating possible responses will allow you to be proactive and control the flow of communication. Taking time to consider your various "audiences" — family members, friends and professional colleagues — can help you find a comfortable way to integrate Parkinson's into the different areas of your life.

Young-onset Parkinson's disease (YOPD) — usually defined as diagnosis at age 50 or younger — may prompt additional considerations about how to handle ongoing obligations to a workplace or young family. (See sidebar, Young-onset Parkinson's Disease, page 15.)



“THE REALITY IS,
SOMEBODY ALWAYS HAS
SOMETHING THAT THEY’RE
DEALING WITH. WE HAVE
TO GAIN STRENGTH
FROM ONE ANOTHER.”



ACTIONS TO CONSIDER NOW

1 Learn about Parkinson's disease.

Information is the best antidote to worry. With knowledge about the disease, available treatment options and ongoing research, you can better evaluate your own symptoms, find the right clinician(s) and develop a treatment plan tailored to your needs. Some people are satisfied with only the basics (or less); others want to wrap their arms around everything there is to know. No matter where you fall on this spectrum, ask your doctor and other people with Parkinson's which sources of information they have found to be the most useful, credible and reliable. Give yourself permission to avoid sources that leave you feeling doubtful, fearful or anxious. And remember: No one else knows exactly how your particular Parkinson's journey will unfold.

REMEMBER TENET #4:
**HONE YOUR NEWS
INSTINCT.**

2 Build a flexible support system that reflects what you need now.

Different people gravitate to different kinds of support (one-on-one vs. group settings, sharing vs. observing, in-person vs. online).

Support systems can evolve over time but they are usually a mix of family, friends, healthcare professionals and, in some cases, paid caregivers, each of whom can be called on as needed at various points in your course with Parkinson's.

3 Assemble the care team that's right for you.

It can be very helpful, at least at the time of initial diagnosis, to see a movement disorder specialist (MDS). Even if you love your primary care physician or general neurologist, seeing an MDS intermittently throughout the course of your Parkinson's disease can be valuable. Because they see more people with Parkinson's, specialists are more attuned to optimizing a care regimen and aware of cutting-edge research that may benefit you. A movement disorder specialist also can help you assemble a care team tailored to your specific needs. For example, if you are having trouble with walking, balance or falls, you might be referred to a physical therapist; home safety issues might lead your doctor to order an occupational therapy home visit; speech therapists can help alleviate voice problems that affect communication; a social worker can help identify supportive resources in your community.

THINK ABOUT TENET #2:
ISOLATION CAN WORSEN SYMPTOMS.

4 Participate in clinical research.

While you may not have given much (or any) thought to clinical trials before diagnosis, research participation is an especially important consideration during the early years of Parkinson's. Trials focused on disease modification or biomarker identification, in particular, often need recently diagnosed individuals who are not yet taking medication. The world of clinical research has expanded to include not only traditional trials at clinical centers but also many opportunities to participate virtually, through online portals, smartphone apps and wearable devices. You'll find lots of information to get started in our *Navigating Clinical Trials Guide* at michaeljfox.org/your-role-research.

5 Consider the pros and cons of genetic testing.

Our Foundation often fields questions from people with Parkinson's on genetic testing (learning whether you carry genetic changes correlated with increased risk for Parkinson's disease). While genetic testing isn't routinely performed during the evaluation and management of PD, it is an integral part of Parkinson's research and drug development. At the current time, having a PD-associated genetic change won't alter your course of treatment. It

“I had to build a new life when I was already pretty happy with the old one.”

— MICHAEL J. FOX

may, however, encourage you to make — or continue — healthy lifestyle changes and connect with clinical trials. (Several genetic trials are ongoing and more are expected to begin within the next few years.) As a part of this collective, your information can be invaluable: An increased understanding of Parkinson’s genetics have informed the majority of research breakthroughs made in the past decade. Genetic testing (with the specific goal of learning this information) and genetics research are two different things, though, and if you choose to participate in the latter but don’t want to know your status for personal or family-related reasons, you can choose not to.

Thinking about delving into your genetic makeup may stir up emotions for you and your family. Talk with your doctor and a genetic counselor about these feelings as well as what Parkinson’s genetic testing can and can’t tell you. Ask about the presently available options for testing — through your provider’s office, an online service or participation in a clinical trial, — the cost (if any) to you, and what the results could mean for you and your family. Find a fuller discussion of Parkinson’s genetics and information about genetic trials at michaeljfox.org/parkinsons-genetics.

6 Exercise regularly.

Exercise offers benefits for everyone. In Parkinson’s specifically, exercise can help sustain mobility and motivation, and improve overall well-being and quality of life. Group exercise can foster social interactions and a sense of community, too. No single form of activity is universally recommended — many types of exercise, at both high and low intensities, done alone or with others, are beneficial for people with PD. The best exercise is the one you will do regularly, so choose something you like and will stick with. To learn about exercises that are popular among people with Parkinson’s and may target specific symptoms, visit michaeljfox.org/exercise.

7 Eat well.

Just as our activity levels impact general health and well-being, so does what we eat. Doctors encourage people with Parkinson’s to follow a well-balanced diet — one rich in vegetables, fruits and healthy fats (found in foods like nuts, avocado and olive oil). Other than that, no specific diet is recommended for Parkinson’s. Once medications are started, though, some considerations around diet may be necessary. (Learn more on page 42.)



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. PPMI gathers data and samples over time from volunteers around the world — both with and without Parkinson’s — to increase understanding of symptoms and progression; find measurements in the earliest stages (even before motor symptoms); and advance treatments to slow, stop or prevent disease.

Whether you have Parkinson’s or care about someone who does, you can help. Find out how and join PPMI, the study that could change everything, at michaeljfox.org/ppmi.



Young-onset Parkinson's Disease

Young-onset Parkinson's disease (YOPD) is generally defined as Parkinson's diagnosed at age 50 or younger. (Average age at diagnosis is around 60.) Distinctive features of YOPD are related to:

Cause.

For every individual with Parkinson's, genetics and environmental factors likely contribute to different degrees to cause disease. In younger people, especially those who have multiple family members with Parkinson's, genetics may play a larger role. If you have YOPD (and particularly if you have a family history of Parkinson's), you might consider genetic testing to see if you carry one of the known mutations that increase risk of PD. Discuss this testing with your family, doctor and genetic counselor — the results might not only be of personal interest to you and your family, they also could offer valuable insights to the Parkinson's research community. (Read more about genetic testing in *Actions to Consider Now*, page 12.)

Path to Diagnosis.

The diagnosis of YOPD may be missed or delayed — physicians and younger people are not typically expecting Parkinson's, and early PD symptoms, especially arm or shoulder stiffness, often are attributed to arthritis, sports injuries or other medical conditions. Attaining a diagnosis may bring feelings of relief, but those with YOPD may be vulnerable to feelings of stigma and alienation. Parkinson's is commonly viewed as an "older person's" disease, and younger adults' symptoms are more likely to be misinterpreted or misunderstood in the day-to-day.

Symptoms and Progression.

The potential movement and non-movement symptoms of YOPD are the same as those of Parkinson's diagnosed later in life. But people with YOPD may be more likely to experience dyskinesia (involuntary, uncontrolled movement) or dystonia (an involuntary muscle contraction that pulls a body part into an abnormal position). In general, the symptoms of YOPD tend to progress more slowly over time.

Medications and Side Effects.

Younger people may delay starting medication and/or begin with drugs other than levodopa, especially if symptoms are mild. This is in part because they are more likely to encounter dyskinesia — involuntary, uncontrolled movements, often writhing or wriggling — as a complication of long-term levodopa use combined with prolonged course of disease. Treatment instead may begin with an MAO-B inhibitor, amantadine, a dopamine agonist or, when tremor is particularly prominent, an anticholinergic drug. (Learn more about Parkinson's medications on page 42.)

Special Considerations.

» Career/Employment.

Whether and when to share a diagnosis in the workplace are nearly universal concerns. (For more, check out MJFF's guides to talking about PD at work at michaeljfox.org/guides.) Depending on specific symptoms and occupation, many people are able to continue working for a significant period of time. Regardless, having a back-up plan, which could include changing schedules or even careers, or seeking early retirement, is worthwhile.

» Finances.

Financial planning may take on a new light, especially factoring in regular doctor visits and medications. It's a good idea to explore long-term care insurance and disability options, even though they may never become necessary.

» Family Planning.

Although the data on pregnancy and PD is limited, plenty of women with Parkinson's disease have successfully carried healthy babies to term. The use of birth control pills doesn't exclude one from taking any

PD drugs, but doses may need adjustment. Couples living with Parkinson's might therefore wish to consider other forms of contraception.

» Parenting.

Parents may worry about caring (both physically and financially) for young children, whether their children are at increased risk for developing the disease, and how to tell them about the diagnosis. Parents in the MJFF community have found it helpful to convey the facts using words directed to the child's level of education, express optimism where possible and offer reassurance on the situation.

Motor and non-motor symptoms may pose logistical challenges when raising children. It may be useful to establish a group of family, friends and neighbors who can help when necessary — such as with babysitting or carpooling — and think about restructuring household roles and responsibilities.

People in midlife may find parenting issues compounded if they are part of the "sandwich generation," caring for or supporting their own parents as well as their children. Social workers can be a good resource to lay out options for these types of situations.

» Relationships and Marriage.

Parkinson's can impact relationships with significant others and spouses. Talking openly and honestly about present and future concerns, as well as addressing symptoms and issues (especially those related to sexual health) as they arise, can be helpful. Cooperation and flexibility — important in any partnership — become even more critical when managing life with Parkinson's together.



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Blazing a Path Parkinson's

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You may be well into your journey with Parkinson's, but could feel as though you're blazing your own trail. Parkinson's is uncharted territory for every individual; it comes without a map to follow or a standard timeline of progression to refer to. PD can be an unpredictable daily companion. It may require you to "roll with the punches" or take your life in directions you may not have planned. But while nobody would ever ask for the diagnosis, many with Parkinson's reflect positively on the relationships it fosters and opportunities it reveals that otherwise would not be possible.

Jimmy Choi
Diagnosed at age 27
Lives in Illinois

The Here and Now: Changes You May Notice as Disease Unfolds

After living with Parkinson's for a while, your symptoms might be affecting some of your physical activities, social interactions or work.

It may be that stiffness and slowness are making morning routines more challenging, or your tremor might be too pronounced to hide, leading you to feel self-conscious. Or, walking and balance problems may develop or intensify. Non-motor symptoms, such as constipation or mood changes, may appear or become more pronounced, even aggravating motor symptoms or impacting the effectiveness of treatments for them. (See sidebar, Non-motor Symptoms of Parkinson's, on page 25.) On the other end of the spectrum, symptoms could be highly manageable and have no significant effect on any part of your life.

If symptoms, for whatever reason, get in the way of doing what you want or need to do, taking medication is an option. Which medication to begin and when are personal decisions that should be made in conjunction with your doctor. A wide variety of Parkinson's drugs exists to choose from; figuring out the ideal one(s) often requires time and effort on the part of both the patient and physician. There is no one-size-fits-all approach. You and your doctor should take into account your symptoms, age, any medical needs and prescriptions you may have outside of Parkinson's, work situation (if applicable) and unique life circumstances, alongside potential benefits and side effects of PD medications.

Almost any of the Parkinson's medications can serve as an initial therapy. For mild symptoms, many people opt for an MAO-B inhibitor, amantadine or an anticholinergic, whereas others elect to start levodopa or a dopamine agonist. Regardless of which drug is chosen, it is prescribed at a low dose and increased slowly until benefit is seen, intolerable side effects occur or a set target dosage is reached. (See the Guide to Medications for descriptions of these and other PD drugs, on page 42.)

If MAO-B inhibitors, amantadine and anticholinergics are no longer adequate for symptom control, levodopa or a dopamine agonist (or increased dosages if they are already being taken) becomes necessary. These drugs can be taken on their own or in combination with other Parkinson's medications, including each other. As disease progresses, medication regimens often must be adjusted to address evolving non-motor and motor symptoms as well as any drug-associated complications that appear. Over time, levodopa may feel less beneficial: Individual dosages may fail to kick in, gradually wear off before the next dose is due, or stop working unexpectedly, leading to more "off" time (periods when symptoms are not optimally controlled). Levodopa also can contribute to dyskinesia, which are uncontrolled, involuntary movements, often writhing or wriggling in nature.

If significant "off" time and/or dyskinesia occur, a variety of management options may be relevant. These include modifications of the drug regimen, enrollment in a clinical trial testing a therapy for these symptoms or deep brain stimulation (DBS) surgery. Many people have experienced a dramatic improvement in symptoms and quality of life after DBS. While this therapy can make a real difference, it is not for everyone, and even good candidates for the procedure still must grapple with the significant decision of whether to undergo invasive treatment. (Find a deeper discussion of DBS on page 36.)

Medical and surgical therapies remain only one component of a Parkinson's treatment program. Regular exercise is a crucial part of the management strategy, especially as symptoms progress. Physical activity and dietary adjustments can help lessen symptoms and maximize medication benefits. (See: Actions to Consider Now on page 22.) Some people also find non-pharmacological interventions, including complementary and alternative medicine, to be helpful in managing their disease. (Check out our Guide to Complementary and Alternative Medicine on page 48.)

REMEMBER TENET #3:
DON'T SETTLE.



“BEING OPEN AND BEING ABLE TO TALK ABOUT PARKINSON’S IS REALLY ALSO A PART OF HEALING.”

Jimmy Choi runs across the marathon finish line. As he walks toward the volunteers handing out medals and water, his body begins to register the nearly four hours of exertion he’s undertaken. But running is when Jimmy feels most in control.

His athletic ability stands in contrast to his everyday challenges, from buttoning shirts to opening jars. Regular visits to his movement disorder specialist help him manage medications so that “off periods” are shorter and he is more productive during the day. His sleep averages four to five hours a night — “very light sleep,” he notes ruefully.

When he was diagnosed at 27, Jimmy shared his condition only with his wife Cheryl and a handful of family members. His physical activity slowed, he gained weight and he began walking with a cane. One day while carrying his infant son, he tumbled down the stairs. Only Jimmy suffered bruises, but he knew it was time to make a change. He began walking, then running, and soon entered his first 5K race.

Jimmy has competed in over a dozen full marathons, over 100 half marathons (and counting), along with countless shorter races in support of research efforts, the PD community and his own well-being.

WATCH MORE OF JIMMY’S STORY AT
[MICHAELJFOX.ORG/PD360](https://michaeljfox.org/PD360).

Emotional and Social Aspects: *What People with Parkinson's Say It Feels Like Over Time*

Life with Parkinson's disease can be an emotional rollercoaster.

As symptoms begin to impact social, occupational or physical activities, you may relive emotions you experienced when you were first diagnosed. Starting medication can trigger a wave of new feelings and a jarring recognition that Parkinson's will remain with you for the rest of your life.

As medication begins to take effect and symptoms ease, though, many people report regaining a sense of control and empowerment. Those who have been hiding their diagnosis now may feel ready to share their news within and outside of immediate family and close social circles.

Many go further, taking on an active role in the Parkinson's community. This may mean telling their story to lessen stigma and others' fears about disclosing a diagnosis, getting involved in policy and advocacy, participating in clinical trials, or launching a community fundraiser to support research or patient service organizations. Pre-eminent journalist — and Parkinson's patient — Michael Kinsley calls this the “confrontation” approach, but admits he prefers denial: “If you're ever entitled to be selfish, I thought (and still think), it's now. So I see good doctors, take my pills most of the time, and go about my business. I couldn't tell you some of the most basic things about Parkinson's and how it works.”

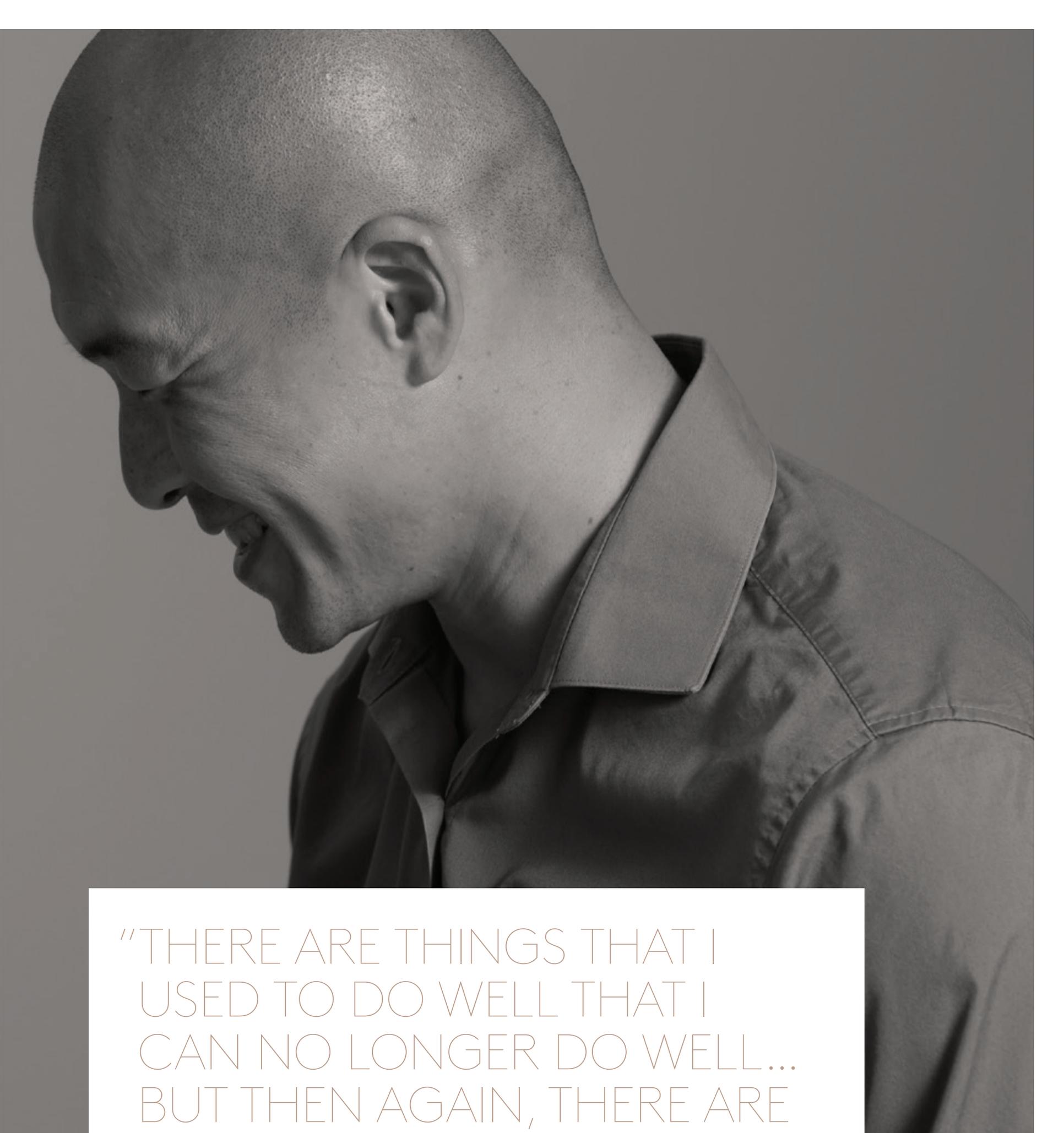
Regardless of how involved you wish to be in your local Parkinson's community, technology has created a host of opportunities to discuss your experiences, connect with others like you (in online support groups, for example), track symptoms and progression, and contribute to Parkinson's research (through smartphone apps and web-based clinical trials). As you enter new communities and forge new partnerships, online or in real life, it's not out of the ordinary to discover yourself assuming new identities and your previous relationships changing shape.

Parkinson's symptoms may or may not interfere with your occupation at this stage, but the potential for this is a common concern, especially among those with young-onset PD. Questions of if, when and how to tell an employer and coworkers about a diagnosis invariably arise. (Check out our guide to disclosing a Parkinson's diagnosis at work at michaeljfox.org/guides.) These are personal decisions based on many factors. Although there is no obligation to bring Parkinson's into the workplace, the stress of hiding it can exacerbate symptoms, and those who reveal their diagnosis often say they wish they'd done it sooner. A general understanding of the Americans with Disabilities Act (ADA)

may be useful should accommodations be required to keep working in the future. Like most massive works of policy, the ADA unfortunately doesn't lend itself to skimming; seek out books or knowledgeable people who can help you make sense of the legislation and get what you need out of it. In short, the ADA protects those who are “disabled,” inform their employers of such and request a “reasonable accommodation” to continue performing their job satisfactorily. The determination of disability is made by individual states according to federal guidelines and requires that a person be impaired in a way that affects daily life. Not everyone with Parkinson's, especially those in early and mild stages, will meet the criteria.

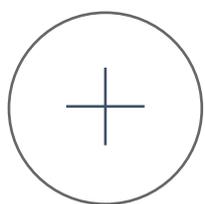
Even when current employment status can be maintained — irrespective of disclosing diagnosis — it's wise to have an alternate plan, whether that means adjustments to your schedule, a change of jobs or early retirement.

CONSIDER TENET #6:
GET ENGAGED.



“THERE ARE THINGS THAT I
USED TO DO WELL THAT I
CAN NO LONGER DO WELL...
BUT THEN AGAIN, THERE ARE
THINGS THAT I NEVER DID
WELL THAT I DO WELL TODAY.”

“Sure, Parkinson’s may be one step forward and two steps back, but I’ve learned that what is important is making that step count.” — MICHAEL J. FOX



ACTIONS TO CONSIDER NOW

1 Modify diet for optimal medication effectiveness.

Once medication is started, dietary modifications may be required to ensure those medications work optimally and to avoid interactions between drugs and certain foods. Levodopa competes with dietary protein for absorption in the small intestine, so taking it with a high-protein meal may reduce how much of the drug gets into your system and how well that particular dose works. When disease is mild, levodopa typically doesn't require separation from meals, but in later stages this may be beneficial. MAO-B inhibitors increase tyramine, and combining them with foods high in tyramine — usually aged cheese and cured meats — could raise blood pressure. These foods don't need to be eliminated from the diet altogether, but should be eaten only in moderation.

2 Continue exercising and adapt as necessary.

As Parkinson's progresses, exercise becomes even more important. Physical activity, along with regular stretching, can lessen motor and non-motor symptoms. Exercise can help to maintain or improve general movement and flexibility, decrease stiffness and improve coordination, gait and balance. It also can ease depression and anxiety, enhance sleep and lessen constipation, apathy and fatigue. Both independent and group activities are beneficial, but the latter has the added benefit of social interaction and even a support system. For examples of exercises that many people with Parkinson's engage in, visit michaeljfox.org/exercise.

3 Add allied healthcare services as needed.

In addition to regular exercise, structured therapy programs designed for people with Parkinson's can help you target specific symptoms. Lee Silverman Voice Treatment (LSVT) BIG physical therapy concentrates on gait and balance issues. SPEAK OUT! and LSVT LOUD speech therapy programs can help counteract loss of vocal volume and clarity. Occupational therapy focuses on ways to help you more easily and safely perform regular daily activities, such as bathing and dressing.

4 Manage financial affairs.

At a certain age it becomes well-advised for everyone to put his or her financial house in order. With that said, living with a chronic disease can add complexity to this process and interfere with your peace of mind. Conferring with a financial planner, accountant, attorney or other professional adviser can help ensure that you and your family have a solid plan in place to meet whatever financial needs may arise.



Non-motor Symptoms of Parkinson's Disease

Not everyone experiences all non-motor symptoms, but over the course of disease (and even before diagnosis) you may live with one or more. Each non-motor symptom can be present at different times and to different degrees.

Sleep disturbances frequently are experienced by people with Parkinson's. Motor and non-motor symptoms, side effects of some Parkinson's medications and conditions associated with PD — restless legs syndrome and REM sleep behavior disorder — can cause difficulty falling asleep, staying asleep or both. **Restless legs syndrome** (RLS) is an uncomfortable sensation in the legs, occurring mainly at night, which resolves only with moving the legs or walking. It may be caused by Parkinson's, the medications used to treat it or a separate medical condition (low iron levels, for example). **REM sleep behavior disorder** (RBD), which often precedes the onset of motor symptoms and diagnosis of PD, causes a person to act out dreams because the normal suppression of muscle activity is impaired. Those with RBD may kick, punch, yell or get out of bed unknowingly during sleep. If RBD poses a safety risk or interrupts a person's or their partner's sleep, Klonopin (clonazepam) or melatonin (an over-the-counter hormonal supplement) is typically recommended. For other sleep disturbances, treatment is targeted at the underlying issue. If nighttime motor symptoms or restless legs are a problem, Parkinson's medications may be adjusted. If depression interferes with sleep, an antidepressant may be prescribed. To maximize sleep in general, it's recommended that you exercise regularly (but not too close to bedtime) and keep a regular schedule where you go to bed and wake up at the same time every day.

Mood disturbances are likely due to both brain chemical changes caused by PD and reactions to physical and mental symptoms

of Parkinson's. **Depression** may cause decreased mood and energy, as well as less interest in previously enjoyable activities. Treatment options include counseling and/or antidepressant medications; regular exercise often is beneficial as well. Most antidepressants can be used in conjunction with any of the available Parkinson's medications, but dosages may need adjustment if MAO-B inhibitors are taken concurrently. **Anxiety** can occur on its own or accompany depression. It might cause uncontrollable worry or feelings of restlessness or being "on edge." A relatively stable level of anxiety often can be managed with antidepressants and/or talk therapy, but for sudden spells of anxiety or panic attacks, anti-anxiety medications, such as benzodiazepines, are sometimes prescribed to use as needed.

Fatigue and **excessive daytime sleepiness** may be a product of sleep and/or mood disturbances, but can be distinct non-motor symptoms of Parkinson's or medication side effects. Treatments may include limiting medications that can cause daytime drowsiness, such as dopamine agonists. In some situations, sedating medications may be added to induce sleep at night or stimulant-type medications prescribed to increase alertness during the day. A strict schedule with a regular bedtime, daytime activities and avoidance of napping (or restriction to short scheduled naps in the early afternoon) is helpful but can be difficult to stick to.

Constipation is part of the underlying disease process. It can predate a diagnosis and

worsen as disease progresses. Not only is it uncomfortable, it also can impact medication absorption and effectiveness. Constipation can be decreased with exercise and dietary modifications, such as adding fiber and probiotic-containing foods, increasing water intake and drinking warm liquid in the mornings to stimulate bowel movements. In some cases, stool softeners, laxatives and/or prescription medications are necessary. Certain medications — anticholinergics and opioid pain medications, for example — can cause constipation, so it is worthwhile to review your list of prescribed medications and make changes where possible.

Low blood pressure when changing positions, or orthostatic hypotension, can be due to Parkinson's and/or the medications used to treat it. It causes lightheadedness, dizziness or fainting. Regular exercise (without excessive sweating) and certain dietary adjustments — increasing fluid (namely water) consumption to six to eight 8-ounce glasses per day and salting food (if heart and kidneys are healthy); avoiding hot or alcoholic beverages; and eating multiple small meals throughout the day (rather than three large ones) — may help. When dietary and lifestyle adjustments aren't enough, drugs may be prescribed to treat orthostatic hypotension. (Read more in the Guide to Parkinson's Medications, page 42.) Some medications — such as diuretics (fluid pills), bladder medications and certain antidepressants — can contribute to low blood pressure and should be decreased or discontinued if possible.

Speech disturbances may include changes in the rhythm, rate, tone and/or volume of speech. Words could become slurred or mumbled. Speech therapy programs can teach exercises and tactics to help you speak louder and clearer and certain devices can improve or amplify communication. Some provide a stimulus to alert you when vocal volume decreases; others feature microphones or tablets for writing or pointing to letters, numbers and symbols.

Drooling may occur in some people in the later stages because saliva is swallowed less frequently. It can be embarrassing and prevent social engagement. Management options may include postural adjustments (keeping the chin up and mouth closed); sugar-free hard candy to stimulate swallowing; or botulinum toxin injections, such as Myobloc (rimabotulinumtoxinB) or Xeomin (incobotulinumtoxinA), or prescription medications to decrease the production of saliva.

Cognitive impairment, a disturbance of memory, thinking and/or language abilities, varies widely in Parkinson's, but generally manifests differently from the memory loss and confusion associated with Alzheimer's disease. It primarily impacts what are known as "executive skills" (organizing, planning, problem solving, etc.), but also can affect attention and concentration, visuospatial function (interpreting where objects are in space), and, to a lesser extent, short-term memory. It can lead to slower thought processing, trouble finding words or difficulty multitasking. Cognitive problems can range



from subtle changes detectable only on formal clinical testing to mild problems that are more than expected with aging but that don't interfere with daily activities (mild cognitive impairment) all the way to significant problems that affect everyday routines, job performance and/or social activities (dementia).

Mild cognitive problems don't always worsen, but if they do, it is more likely to happen in the later stages of Parkinson's. No medications are currently available to treat mild cognitive symptoms, but there is some evidence to support the idea of "exercising your brain" to maintain cognitive fitness. Take an expansive approach: Attending a get-together where you'll have to remember the names of new acquaintances and make sparkling conversation about current events can be every bit the cognitive workout a crossword puzzle is, and has the added benefit of keeping you social. Regular

exercise and a healthy diet also are recommended for brain health. (Find further discussion of Parkinson's disease dementia on page 28.)

Hallucinations and delusions can be associated with Parkinson's. If they do occur, it is more likely to happen in advancing stages. Visual hallucinations (seeing things that aren't there) and delusions (firmly held, false, often paranoid, beliefs) are the typical manifestations of what is known as Parkinson's disease psychosis. Psychosis may be due to Parkinson's disease itself and/or the medications used to treat it. (Learn more about psychosis on page 29.) Decreasing or discontinuing certain Parkinson's medications may help, but this is often at the expense of worsening motor symptoms. If medication adjustments are inadequate or symptoms of psychosis are especially severe, antipsychotics may be prescribed. (See the Guide to Medications, page 42.)



*03. Living
with
Disease*

Looking Ahead Parkinson's

Case

The passing of time brings natural changes and life transitions for everyone (Parkinson's or not). For people with PD, these shifts may occur earlier than expected or be more challenging. If you've had Parkinson's for quite a while, you've likely gotten to know your symptoms — and also often the best management strategies — well. As time marches on, symptoms may change or progress. Be confident in your past experiences overcoming challenges and take heart in the knowledge that treatment options are expanding for symptoms at all stages of the disease.

Lisette Ackenberg
Diagnosed at age 50
Lives in California

The Here and Now: Parkinson's Changes that Can Emerge with Time

Some people who have had Parkinson's for several years still work, raise families and run marathons.

You could be bothered by tremor but have no walking problems or vice versa. Each individual's symptoms, as well as the severity and rate of progression, remain distinct throughout PD's course. That being said, after years or decades with PD, you may experience a need for varying levels of assistance. Help could come in the form of your spouse buttoning your shirt because poor dexterity makes dressing tedious or a decision to move to an assisted-living facility. These considerations could come up earlier in the course of disease for some and never arise for others. What's important is to stay in tune with your own symptoms and situation. Stay on your own path. Someone else's course doesn't dictate yours.

REMEMBER TENET #1:
**THERE IS NO "ONE SIZE FITS ALL"
DESCRIPTION OF PARKINSON'S
DISEASE.**

Some people may experience different degrees of **balance or walking problems**. Imbalance causes unsteadiness, which makes walking a straight line tricky. Walking changes can include shuffling, difficulty getting started (hesitation), a sudden inability to move (freezing) or short, accelerating steps that are hard to stop (festination).

Difficulties with walking and balance can increase the risk of falls, which in turn could cause injuries, hospitalization or, eventually, the loss of independence (in other words, the need for living arrangements other than one's own home). Unfortunately, these symptoms are tough to treat — for most, they don't significantly improve with the current medications and surgical therapies. Yet, they can be managed by optimizing Parkinson's drug

regimens, exercising regularly, learning fall-prevention strategies and using assistive devices (such as a cane or walker) if necessary. Participating in physical or occupational therapy, specifically with a therapist who has expertise in neurological disease, can make a substantial difference as well. (Find a detailed discussion of gait and balance issues at michaeljfox.org/walking-and-balance.) Occasionally, changes in balance or walking are due to conditions other than Parkinson's, which require a different treatment course. Don't automatically assume everything you experience is part of your PD — discuss all symptoms and any worsening with your movement disorder specialist, who can determine what's part of Parkinson's and what might be something else.

For some people, issues related to swallowing also could arise. **Swallowing difficulties** may manifest in several ways — coughing or choking while eating or drinking, throat clearing or a sensation of food getting "stuck" while going down. If these occur, a speech-language pathologist can check how well you tolerate solids and liquids of different consistencies and your doctor can order imaging tests, such as a videofluoroscopic, or a modified barium swallow study, to determine where problems are happening (such as in the mouth while chewing or in the throat while swallowing) and if liquids and/or foods are going into the lungs instead of the stomach (if you are "aspirating"). Based on these results, dietary modifications and adaptive strategies can be recommended to lessen the risk of aspiration, which could otherwise potentially lead to pneumonia. If you experience frequent episodes of aspiration pneumonia or have severe weight loss, a feeding tube may be suggested. But just because you have

a problem swallowing does not mean you will need a feeding tube. Since swallowing disturbances could pose choking risks and the Heimlich maneuver can be life-saving, care partners may want to learn this technique.

Non-motor symptoms also may be noticed. One particular symptom that some, but not all, people encounter after living with Parkinson's for many years is **Parkinson's disease dementia (PDD)**. If mild cognitive impairment worsens over time, it can (but doesn't always) morph into PDD, which causes memory, thinking and/or language problems significant enough to interfere with daily life at home, work or in social circles. Like milder cognitive impairment in Parkinson's, PDD can impact executive skills (such as organizing, multitasking and problem solving), visuospatial function (interpreting where objects are in space), attention and short-term memory, but to a more considerable extent. It also may cause behavioral, mood and motivational changes. If PDD occurs, it's typically after a person has had Parkinson's for many years. When dementia arises at the same time as or within a year of the onset of motor symptoms, it could instead be due to dementia with Lewy bodies (DLB), a form of atypical parkinsonism. (Learn more about atypical parkinsonism at michaeljfox.org/atypical-parkinsonism.) In addition to Parkinson's motor symptoms and dementia, DLB can be characterized by fluctuating levels of alertness and visual hallucinations (seeing things that aren't there).

Visual hallucinations might be associated with DLB and PDD, but they can occur in the absence of dementia — either as a side effect of Parkinson's (or other prescription or over-the-counter)

medications or as a distinct symptom of the disease, known as **Parkinson's disease psychosis**.

Psychosis, if it does occur, is more common in advancing disease and in conjunction with significant cognitive changes. In addition to hallucinations, this aspect of Parkinson's can include illusions (misinterpreting things that are there), a false sense of presence (feeling as though someone or something is nearby) or delusions (strongly held false beliefs, usually expressed as paranoia or suspicion about financial issues or spousal infidelity).

It's important to stress this is a symptom of Parkinson's disease and does not mean a person is "going crazy." Symptoms are treatable. Doctors will first adjust medications, reducing or withdrawing those that are most likely to contribute to psychosis, such as dopamine agonists and anticholinergics. If motor (and other) symptoms worsen significantly as a result of these modifications, adding antipsychotic drugs may be necessary. Nuplazid (pimavanserin), the first drug approved specifically to treat hallucinations and delusions due to Parkinson's disease psychosis, hit the U.S. market in 2016. Other antipsychotics, including Seroquel (quetiapine) and Clozaril (clozapine), were used prior to Nuplazid and may still be prescribed in certain situations. (Read more about all of these drugs in the Guide to Medications on page 42.)



"I DON'T STOP LIVING BECAUSE OF PARKINSON'S."

Lisette Ackerberg lived with Parkinson's disease for a decade before telling her family and friends. She had watched her grandfather and her father live with Parkinson's for years, and never wanted loved ones to look at her with sympathy. So when she finally made her announcement, she did it with bravado at her 60th birthday party.

Her concerns about others' perceptions, along with her symptoms, have shifted over the nearly three decades she has lived with PD. Today, symptoms and medication side effects can make shopping or other daily tasks difficult. An inability to anticipate dyskinesia has curbed her spontaneity. But through it all, she remains positive. "You have to know that this disease isn't a death sentence. It just means you alter your life. You change it so it works."

In 2004, within a single month, Lisette lost her father to Parkinson's and her husband to multiple sclerosis. The immense stress seemed to catapult the disease, but now she credits that time with helping her define her personal formula for managing her PD: sleep, strong exercise, good food and a conscious effort to stay positive.

She took up walking, and walked in a 5K for Parkinson's on her 75th birthday, "in the hail," as she recalls. "I was very proud of that." But as she approaches her eightieth birthday, Lisette no longer feels any pressure to prove herself. "I exercise everyday but I don't walk those distances."

And with that, she left her interview to continue planning another birthday party, this time for her mother's 98th.

WATCH MORE OF LISETTE'S STORY AT
[MICHAELJFOX.ORG/PD360](https://www.michaeljfox.org/pd360)

Emotional and Social Aspects: *What People with Parkinson's Say It Feels Like* *After Many Years*

Parkinson's disease will include periods of challenging adjustment and transition; this realization alone can increase your creative coping skills.

Making changes in routine or treatments could go a long way toward helping you live well. Avoid isolating yourself. Engaging with others is critical to ensuring both mind and body well-being; talk with your doctor about any symptoms that are preventing you from enjoying activities with family and friends so you can work together to address them. It's normal to feel frustrated, especially if you begin to experience symptoms that interfere with social interactions, but you needn't feel hopeless.

REMEMBER TENET #5:
PARKINSON'S IS A NON-LINEAR DISEASE.

Depending on which symptoms are present, different types and levels of support may be necessary. Some people may need help with household duties like laundry, grocery shopping or bill paying. Others might require help with showering and dressing, or preparing and eating meals.

Within the home, spouses or live-in partners usually supply the majority of assistance. If finances allow, you might consider hiring a home health aide or certified nursing assistant to help with certain tasks, such as transferring out of bed or bathing. (A social worker can direct you to the right resources and necessary paperwork.) If you as a caregiver simply need a chance to run errands, do household chores, socialize with friends or get some exercise, you could ask a friend or family member to come over a few times a week. In some cases the support of a skilled medical professional is necessary. After a hospitalization or fall, for instance, a nurse might monitor blood pressure to guide medication adjustments or a therapist may teach rehabilitation exercises to help you regain strength and mobility. Insurance usually covers a set number of these professional visits each year.

Growing care needs or certain symptoms — such as walking or balance issues that increase risk of falls, cognitive problems, or hallucinations or delusions — may affect a person's ability to continue living alone or at home. In these instances, assisted-living or skilled-nursing facilities may provide

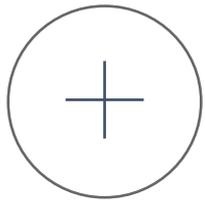
alternative solutions. Assisted-living varies, but often includes meals, medication administration and some personal care. Skilled-nursing facilities provide full medical care and 24-hour supervision if greater levels of attention are required.

Medication adjustments may be necessary to meet evolving non-motor and motor symptoms as well as any drug-associated complications that appear. An expanding repertoire of treatments, including several new formulations of levodopa, now exists that can be transformative for people throughout the course of Parkinson's. (Learn more about Parkinson's medications in our Guide to Medications on page 42.) More research than ever before is actively under way to develop therapies capable of meeting the needs of Parkinson's patients at every stage of disease (and to find treatments that would prevent the disease from advancing into the later stages in the first place). "The latest research is the latest hope," says Michael J. Fox. Keeping hope alive is vital to wellness for everyone with PD, especially those who may be in the later years of disease.



"AS THE DISEASE
PROGRESSED, I
REALIZED THAT I WAS
AS VULNERABLE AS
ANYBODY ELSE."





ACTIONS TO CONSIDER NOW

1 Keep up with exercise.

Regular exercise remains an important tool for managing progressing Parkinson's. No matter what symptoms are present and how significant they may be, some form of exercise likely can be done. Your doctor and physical therapist can help create a program to suit your fitness level and symptoms. If balance is an issue, stretching exercises can be performed on a floor mat; many physical activities — yoga, dancing and cycling — can effectively be done while seated. (There's more information on exercise at michaeljfox.org/exercise.)

2 Continue adjusting diet as needed.

For constipation and low blood pressure, increased water intake and other dietary adjustments (typically along with pharmacological management) are recommended. Swallowing dysfunction may dictate changes in diet consistency (thickening liquids or softening solids, for example). The increasing occurrence of "off" time (periods when medication doesn't work optimally to control symptoms) may signal the need to take levodopa separate from meals, particularly those high in protein, which can interfere with the drug's absorption and effectiveness. In these cases, take

levodopa on an empty stomach (30 to 60 minutes before or after a meal) or with a small carbohydrate snack (such as crackers, oatmeal or toast). Another option is to save higher amounts of protein for the end of the day, when symptom control may not be as critical. Some people adopt vegetarian eating habits, but depending on the content (beans, nuts, cheeses, etc.), these diets can still be high in protein.

3 Keep your financial house in order.

Some healthcare and life insurance policies cover a portion of costs related to caregiving (a certain number of home visits from skilled medical professionals or a percentage of assisted-living or skilled-nursing facility costs, for example). Disability policies don't cover any of these expenses and long-term care plan benefits vary. Individuals and their families are therefore ultimately responsible for meeting the majority of caregiving costs. Many turn to savings, reverse mortgages, annuities or trusts.

End-of-life financial planning shouldn't be overlooked. A power of attorney for property can be appointed to manage money, investments and businesses. A written will can ensure your estate will be divided according to your wishes.

4 Don't forget the caregiver.

In the midst of looking after another's medical, physical, emotional and financial concerns, the caregiver can get lost or be forgotten. Caregivers have to make a conscious effort to see to their own needs and speak up for themselves. Keeping up social activities and hobbies, exercising regularly, taking breaks, scheduling routine doctors' appointments to maintain your health and building a strong support system (including a caregiver support group, if that's helpful) are key. Use this opportunity to evaluate your personal finances and long-term care insurance options. It is also critical to recognize limitations and monitor for caregiver burnout, which can manifest as fatigue, irritability or depression.

5 Explore palliative care.

Palliative care is not the same as hospice. While hospice is for those with a prognosis of six months or less, palliative care services can be accessed at any time in the course of disease. Palliative care teams (usually consisting of a physician, nurse, social worker and clergy member) provide medical, emotional and spiritual care to people with Parkinson's and their loved ones. Medical support is focused primarily

“The reality is that things change; the question is, how will I perceive that change, and am I willing to change along with it?”

— MICHAEL J. FOX

on lessening particularly troublesome problems, such as significant cognitive, behavioral or sleep disturbances, psychosis or disabling motor symptoms.

Define end-of-life care wishes and advance directives.

Every one of us, Parkinson's or not, will face the end of life. Setting intentions for that time and beyond can help mitigate fear. Thinking ahead and working through possible scenarios to determine your preferences about care in the final phases of life often are beneficial to you and your family. Palliative care clinicians can help facilitate conversations to guide current and future care.

It is natural and fair to wonder aloud in these discussions whether you will die from Parkinson's and, in fact, this is a question that is regularly asked. Of course, it's impossible to predict any one individual's outcome. On the one hand, many people with Parkinson's who are optimally treated

may have a nearly normal lifespan. On the other, those who have particularly advancing disease are, in general, more likely to experience and succumb to certain conditions. Significant walking and balance issues and resultant decreased mobility can lead to urinary tract infections, falls and injuries, and pneumonia. Swallowing problems can cause aspiration pneumonia. Infection, injury and other illnesses can be difficult for someone in the later years of Parkinson's to recover from fully or at all. Measures can be taken to prevent these conditions, or, if they do occur, to treat them or minimize their effect. Plenty of people will never experience any of these complications. But equipped with this knowledge, you can plan for potential — but not inevitable — situations and make informed decisions about your personal goals of care.

As you do so, completing advance directives — written legal documents that detail your wishes — is often beneficial. A living will specifies whether and which life-support measures (breathing or feeding tubes, intravenous hydration, etc.)

a person wants in the event he or she is seriously ill and cannot communicate. A Do Not Resuscitate (DNR) order indicates that cardiopulmonary resuscitation (CPR) should not be done if the heart and/or breathing stop. (Of course you'd only complete this if it were consistent with your wishes.) A healthcare power of attorney — someone to speak for you if you are not able and to fulfill your advance directives — can be designated as well. Legal counsel isn't required to complete advance directives but can be sought if helpful. These documents should be shared with your physicians and placed in the medical record. Advance directives do not expire but can be changed at any time.

Having these plans in place can be comforting. Both family and physicians are often grateful to know they are carrying out directed plans, if that becomes necessary.

REMEMBER TENET #7:
BE PREPARED.

Hospitalization and Surgery in Parkinson's Disease

Hospitalization

Hospitalization is not inevitable in Parkinson's disease, but should you find yourself in the emergency department or hospital, some special preparations can help ensure the best possible care. The hospital doctors can discuss your care with a neurologist — either your

personal movement disorder specialist or a hospital consultant — if necessary. Be ready to play an active role in this conversation and to advocate for your (or your loved one's) needs.

Deviating from your normal drug regimen or taking new medications while in the hospital could temporarily worsen Parkinson's symptoms. The following tips may be helpful during hospitalization:

- » Share a list of your current medications, supplements and drug allergies with your hospital providers.
- » Take all medications in their bottles with you to the hospital.
- » Request that medications be administered per your home schedule rather than the hospital's standard schedule (if these are different).
- » If the hospital pharmacy does not carry one of your medications, ask if you can bring your own supply.
- » Avoid certain anti-nausea medications and antipsychotics (which may be used to treat hallucinations, confusion and sometimes also sleep problems) if possible, as they can temporarily worsen motor symptoms.
- » Use medications for pain or sleep carefully as these can cause excessive sleepiness and confusion.

Urinary tract infections (UTIs), pneumonia and injuries from falls are common precipitants for hospitalization in people with Parkinson's. UTIs and pneumonia are typically treated with antibiotics. For aspiration pneumonia, speech therapy and dietary modifications also may be recommended to help prevent future infections.

Because falls most often result from walking and balance problems, a physical therapist is usually consulted during hospitalization. The therapist may teach exercises, evaluate the need for an ambulation aid (such as a cane or walker) and provide recommendations about when you can safely leave the hospital and whether you need additional rehabilitation. After hospitalization, some people go to a rehabilitation hospital or skilled-nursing facility for additional physical therapy. Others are able to return home and get physical therapy there or in an outpatient clinic. The selection is made based on several factors, including a person's symptoms and support system at home.

Confusion, excessive sleepiness or hallucinations can develop or worsen during hospitalization because of the unfamiliar environment, altered sleep schedule or new medications. Family can help limit confusion by making sure eyeglasses and hearing aids (if applicable) are available and, although not easy, nurses can try to maintain the person's normal sleep routine. If confusion or hallucinations lead to agitation or other behaviors that compromise safety, treatment (including antipsychotic medications) may be required.

For those with deep brain stimulators, the device may need to be temporarily turned off so that certain medical tests, such as heart EKGs or brain EEGs, can be performed. MRIs of the brain or other body parts may be permitted but this depends on the specific DBS device. Strict protocols will be followed to ensure the test is completed safely, so make

sure that the hospital and radiology staff are aware you have had DBS.

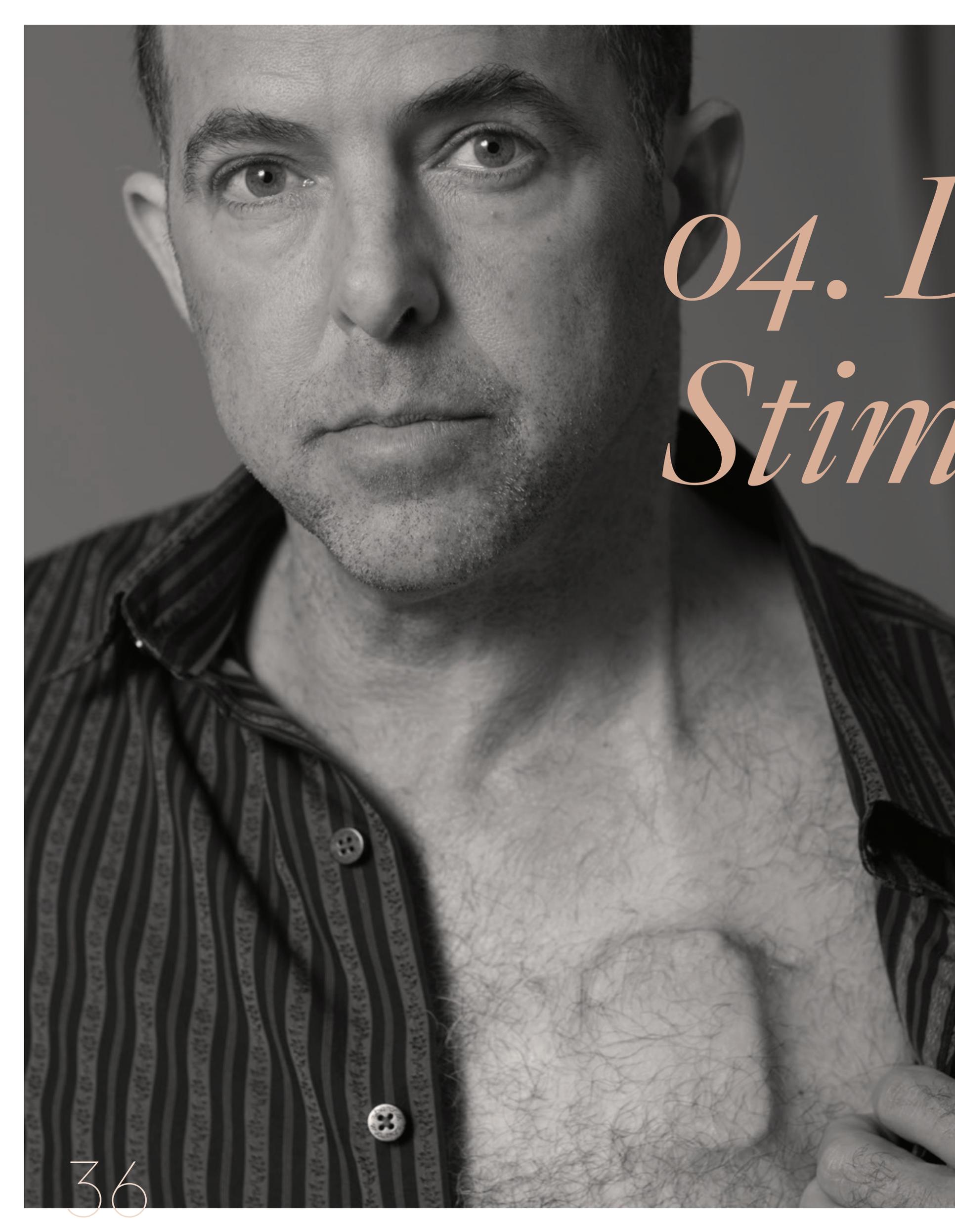
Surgery

The risks and benefits of any surgical procedure should be carefully considered with your movement disorder specialist and surgeon prior to the operation.

If it's an option, local anesthesia may be preferred over general as the latter could increase the risks of temporary confusion and possibly pneumonia in the post-operative period.

Most Parkinson's medications are continued until the night before surgery, with the exception of MAO-B inhibitors, which may need to be held for up to two weeks beforehand. If possible, medications should be restarted immediately following surgery. If you can't take anything by mouth or swallowing is an issue, some drugs can be crushed and given through a tube. Others are available as dissolvable pills or can be administered through a skin patch. Certain capsules can be opened and the contents sprinkled on applesauce or food of similar consistency for immediate use. (Read more about these and other Parkinson's drugs in the Guide to Medications on page 42.) Anti-nausea medications are commonly given post-operatively but some should be avoided as they can temporarily worsen Parkinson's motor symptoms. It's important to ask your doctor what medications are being prescribed and why while you are in the hospital.

In the post-operative period, those with PD (especially in the advancing stages), may have an increased risk of confusion and longer healing times compared to people without Parkinson's. Working with a physical therapist to ensure you maintain mobility and consulting a speech therapist with any concerns about swallowing may help you get on the road to recovery more quickly.



04. L
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Deep Brain Stimulation

Over time, medications may become less successful than they once were at controlling symptoms or cause increasingly disabling complications, such as dyskinesia. This can happen at different points in the disease course. If it does, deep brain stimulation (DBS) — today’s most common surgical treatment for PD — may be considered. As with all of the currently available Parkinson’s treatments, DBS addresses symptoms but is not a cure; the underlying disease continues to progress. While stories of DBS as a “miracle treatment” are common, DBS is not for everyone.

Richie Rothenberg
Diagnosed at age 43
Lives in California

According to the company that manufactures the vast majority of DBS devices, more than 150,000 DBS devices worldwide have been implanted to date. For people with Parkinson's, the surgery can improve motor function and quality of life. It also can dramatically reduce medication requirements and associated side effects or complications, for a period of time — often years. Several factors are considered when determining whether someone is a good candidate for the procedure.

Diagnosis of Parkinson's disease

People with atypical forms of parkinsonism, or "Parkinson's plus" syndromes, do not benefit from this therapy. (Learn more about atypical parkinsonism at michaeljfox.org/atypical-parkinsonism.)

Presence of Parkinson's for at least four years

Symptoms should be established, but the disease should not be so progressed as to cause considerably decreased mobility or reliance on a wheelchair. DBS generally cannot reverse these situations.

Continued medication benefit

DBS typically treats symptoms that get better with medication; it does not improve symptoms (with the exception of tremor) that don't respond to medication. (In other words, tremor that doesn't improve with medication may respond to DBS.) It works best for motor symptoms — slowness, stiffness and tremor. It doesn't work as well for imbalance, most walking problems or freezing of gait. Non-motor symptoms often don't respond and some, such as

memory, thinking or speech disturbances, may even worsen following surgery.

Intact cognition (memory/thinking abilities)

DBS can potentially exacerbate underlying cognitive problems. People with dementia may not do well with the surgery or intricacies of DBS.

Overall medical condition conducive to surgery

Certain heart diseases or problems with the blood's ability to clot might make surgery too risky.

Some people are not ideal candidates because they don't meet the criteria above. Others cannot or do not want to undergo the surgery to implant the device, periodic programming of DBS settings or future battery replacements.

When thinking about DBS, some people with PD report a wide range of emotions. Hope and optimism for how the treatment may help are common, but so are a dawning sense of the realities around the progression of the disease, grief over the loss of ability to manage symptoms with

medication alone, and a natural trepidation at the idea of undergoing brain surgery.

If you are considering DBS, it is vital that you give yourself every opportunity to thoroughly assess the potential pros and cons. Discuss the procedure with your spouse, family and friends; draw on the experiences of others with PD who have had DBS; and, if possible, attend an educational seminar where you can learn more about the procedure and talk to others who are considering it as well. Ongoing conversations with the doctor who treats your Parkinson's disease also are critical to ensure all of your questions and concerns are addressed.

If you are a good candidate and decide to pursue DBS, a team of doctors will perform an intensive evaluation, including symptom and medication review, examination while on and off Parkinson's medication, brain imaging, and often also detailed memory and thinking (neuropsychological) testing. If DBS is offered, it's important to discuss anticipated benefits and to set realistic expectations. As with so many elements of Parkinson's disease, each person's response to the therapy will be unique and certain people may respond more favorably than others.

What to expect in the operating room and beyond

In DBS surgery, thin wires called electrodes are placed into one or both sides of the brain in specific areas that control movement. The patient usually remains awake during surgery to answer questions and perform tasks that ensure the electrodes are positioned correctly. (Some centers are now placing electrodes under imaging guidance, which allows a patient to be asleep during the procedure.) Electrodes are then connected to a battery-operated device, similar to a cardiac pacemaker, which is placed under the skin in the chest. This device — the neurostimulator — delivers carefully controlled electrical pulses that interrupt abnormal brain cell signaling and decrease PD symptoms.

A few weeks after surgery, a movement disorder specialist programs settings into the neurostimulator. These parameters, which are customized to treat each individual's symptoms, are tweaked over time while medications are adjusted. Most people are able to decrease (but not completely discontinue) Parkinson's drugs. Determining the optimal combination of medications and DBS settings — that which gives the most benefit with the fewest side effects — is a process that can take up to a year. Periodic programming adjustments are a routine part of therapy and eventually the neurostimulator battery will need to be replaced. This is typically an outpatient procedure, and the timing of this varies depending on the device and a person's settings.



"I'M A RISK-TAKER."

At 44, seven years after being diagnosed with Parkinson's disease, Richie Rothenberg felt encumbered by his body. He often found himself freezing without warning while powerful dyskinesias took over his body. "It was a very difficult time," he remembers.

While deep brain stimulation (DBS) isn't right for everyone, Richie's intense response to levodopa therapy meant he was an excellent candidate. On his doctor's recommendation, Richie decided to undergo the procedure in December 2010.

Unfortunately, after surgery he came down with a staph infection — a complication experienced by a small percentage of people who undergo any surgery — and spent New Year's Eve getting the whole apparatus taken out.

"I had to wait another six weeks before I could be ready to do it again," he recounts. The good news? He had done so well in the first surgery that doctors were able to redo the operation and implant the battery in one procedure the second time. "My endurance was

proven that I could stand a six- to eight-hour procedure. It's a long procedure," he says. The results were dramatic. Richie was among the rare patients who experience an immediate benefit, even before doctors had programmed his device.

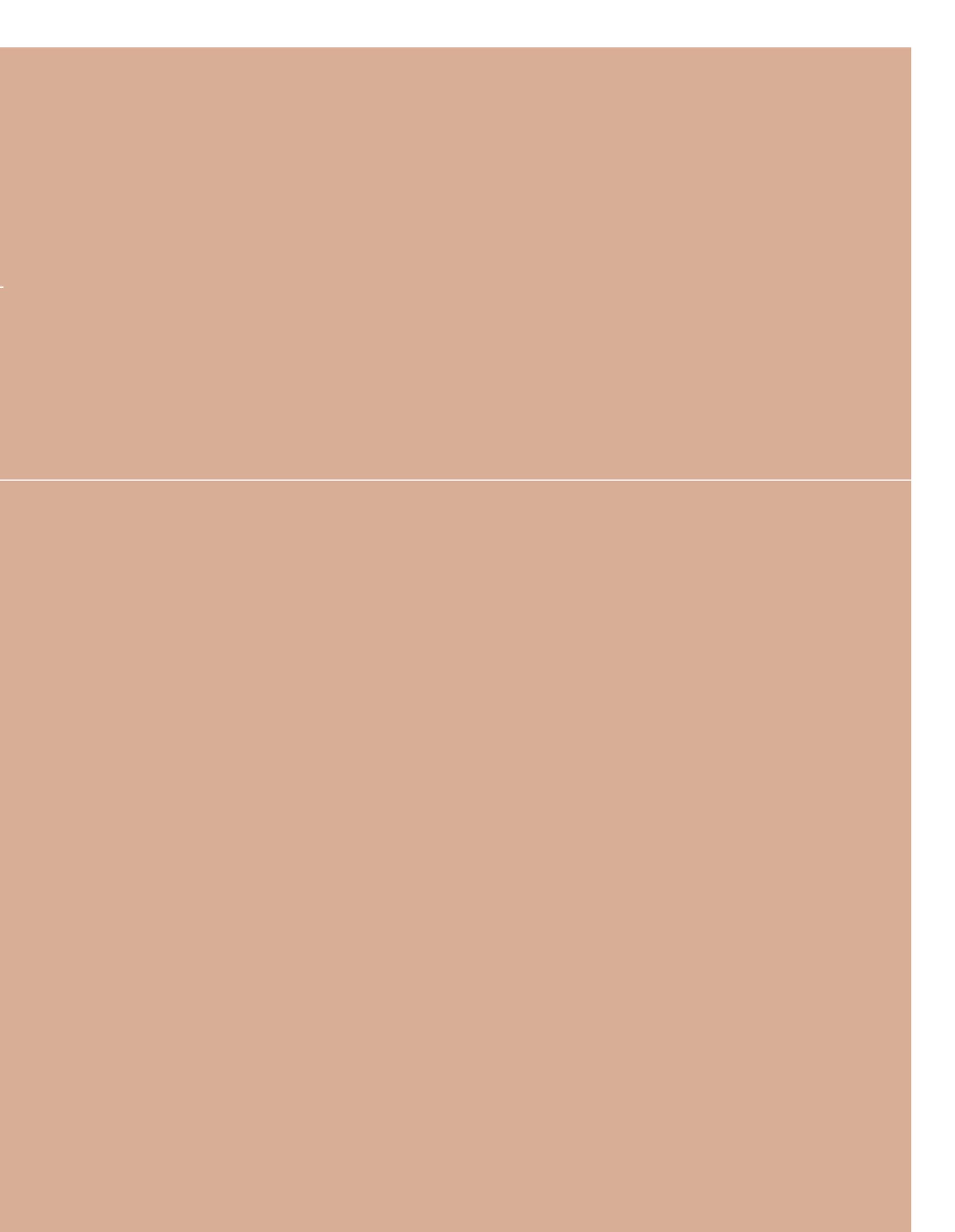
It took a couple of years to get back to that instant moment. "The body settles down, the brain, the excitement settles down," he explains. "It took about two years of going in every month or so for a different tweaking of the DBS settings." He now undergoes regular outpatient procedures to maintain the pacemaker-like DBS device.

A year and a half after his operation, he married his high school sweetheart. He balances his professional life with his personal life, parenting their twin daughters and two children from a previous marriage. "Parkinson's is the best thing that ever happened to me," he says. "It changed my life in a profound way that made it much more meaningful and much more appreciative and filled with love."

WATCH MORE OF RICHIE'S STORY AT
MICHAELJFOX.ORG/PD360.

For Your Reference

*Information on medications,
surgeries, and complementary
and alternative therapies*



GUIDE TO PARKINSON'S MEDICATIONS AND SURGERIES

All of the treatments currently available for the management of Parkinson's disease are directed at improving quality of life by easing the motor and non-motor symptoms that can arise throughout the course of the disease. At this time, no disease-modifying therapy — one that stops or slows PD progression — has been proven, but research in this area is extremely active and promising. For the latest in research and new therapy approvals, visit michaeljfox.org.

MOTOR TREATMENTS AND ASSOCIATED COMPLICATIONS IN THE EARLY AND MIDDLE YEARS

Medications for the treatment of motor symptoms are grouped into different categories according to the ways in which they work to lessen symptoms. Levodopa, a precursor to dopamine (the brain chemical that is lacking in PD), is the most commonly prescribed. At some point in the course of disease, most people will take this drug. Levodopa is generally quite beneficial, especially for treating stiffness and slowness. It also doesn't require a long period of adjusting the dose to get symptoms under control. Long-term use of levodopa, in conjunction with prolonged duration of Parkinson's, though, may be associated with motor complications, such as dyskinesia. Other medications that target motor symptoms (and can be used in conjunction with and, in some cases, instead of, levodopa) include dopamine agonists, MAO-B inhibitors, amantadine, anticholinergics, adenosine receptor antagonists and COMT inhibitors. With the exception of the last two, any of these may be selected as the first therapy. The choice is based on many factors, including the type and severity of a person's symptoms, other medical conditions and prescriptions, age and personal preference.

Physicians and researchers have long engaged in a healthy discussion over

whether it's better to start levodopa sooner to control symptoms; maximize quality of life; and allow a person to remain physically, socially and occupationally active as long as possible, or to avoid levodopa as long as possible to delay potential motor complications. Younger people or those with milder symptoms may choose to start with a dopamine agonist, MAO-B inhibitor, amantadine, or in the case of prominent tremor, an anticholinergic. Or, for one reason or another, they may opt to start with levodopa. Ask your physician for his or her take on this issue and consider the pros and cons of both approaches.

Decisions about if, when and which medication to take are personal. Regardless of which therapy you choose, the drug will be started at a low dose and increased slowly so that the smallest effective dose — that which controls symptoms with minimal or no side effects — can be found. Over time, as symptoms progress or complications arise, medications need to be adjusted: dosages increased or decreased, daily administration schedules changed, drugs added or substituted, or different formulations tried. The latter might include switching to an extended-release form of levodopa or to a dopamine

agonist from an immediate-release levodopa preparation if that's not optimally controlling symptoms (it's wearing off before the next dose is due, for example). Or, if swallowing becomes difficult, a dissolvable pill or skin patch may be prescribed instead of an oral pill.

Finding the right formulations, dosages and combinations of medications is a process that requires time and effort on the part of the person with Parkinson's, his or her caregiver, and the medical provider.

Dopamine Replacement Therapy (levodopa/carbidopa)

Levodopa is a drug that is converted to dopamine in the brain; it temporarily replenishes this brain chemical, which is decreased in Parkinson's. Levodopa is combined with carbidopa, a medication that prevents levodopa from breaking down before it gets to the brain and limits levodopa's side effects. Levodopa is available in immediate, controlled and extended-release preparations as well as a variety of formulations that include pills that are either swallowed or dissolve in the mouth, a gel for continuous intestinal infusion and an inhaler. The gel

for intestinal infusion (Duopa) typically is an option in advancing disease if other medications can't control symptoms or complications (such as dyskinesia and/or "off" time) occur. The inhaled levodopa (Inbrija) is a rescue medication to use as needed, in addition to other Parkinson's medications, for "off" time, when symptoms return between medication doses. Nausea and vomiting are the most common side effects of levodopa. These often resolve with time, but if not can usually be managed by taking levodopa with a small carbohydrate snack or extra carbidopa. Other potential side effects are drowsiness, hallucinations, dizziness, low blood pressure and impulsive behaviors — such as excessive shopping, eating or interest in sex. (These are more likely in middle or advancing stages of disease but not everyone will experience any or all of them.) Long-term use of levodopa, in conjunction with longer duration of Parkinson's disease, may lead to changes in medication response called motor complications. These include "off" time (when drugs aren't working optimally and symptoms return) and dyskinesia (uncontrolled, involuntary movements).

Examples of dopamine replacement therapies:

- » **Duopa (levodopa/carbidopa):** gel for continuous intestinal infusion
- » **Inbrija (levodopa):** as-needed inhaler for "off" time
- » **Rytary (levodopa/carbidopa):** immediate- and extended-release levodopa in one pill
- » **Sinemet (levodopa/carbidopa):** pill or dissolvable-in-mouth pill; immediate- or controlled-release formulations
- » **Stalevo (levodopa/carbidopa and entacapone, a COMT inhibitor):** pill

Decarboxylase Inhibitor

This medication prevents the breakdown of levodopa in the body so that more levodopa can get to the brain and be converted to dopamine. It also helps prevent or minimize side effects of levodopa, such as nausea and vomiting. Carbidopa is usually combined with levodopa in the dopamine replacement therapies listed previously but if bothersome side effects (namely nausea and vomiting) occur with these drugs, extra carbidopa may be prescribed.

Example of decarboxylase inhibitor:

- » **Lodosyn (carbidopa):** pill

Dopamine Agonists

These drugs mimic the effect of dopamine in the brain. They are available in immediate- and extended-release preparations, and in the form of pills, a skin patch, an injection and an under-the-tongue dissolvable strip. Apokyn (injectable apomorphine) and Kynmobi (sublingual apomorphine) can be used as needed, in addition to other Parkinson's medications, for "off" time. Compared to levodopa, this class of drugs may be slightly less effective at reducing PD symptoms but also is much less likely to induce motor complications over time. Potential side effects of dopamine agonists include nausea, drowsiness, leg swelling, low blood pressure, hallucinations and impulse control disorders, such as compulsive gambling or eating, excessive shopping or increased interest in sexual activity. The dosages of some of these medications need to be lowered if kidney function is impaired. Some people may benefit equally from all of the currently available dopamine agonists; others might develop side effects from one and not the others. Whichever is chosen is initiated at a low dose and increased gradually over weeks or months until symptoms respond, side effects arise or a target dosage is reached.

Examples of dopamine agonists:

- » **Apokyn (apomorphine):** as-needed injection for "off" time
- » **Kynmobi (apomorphine):** as-needed under-the-tongue dissolvable strip for "off" time
- » **Mirapex or Mirapex ER (pramipexole):** pill; immediate- or extended-release formulations
- » **Neupro (rotigotine):** skin patch; extended-release formulation
- » **Requip or Requip XL (ropinirole):** pill; immediate- or extended-release formulations

MAO-B Inhibitors

This class of drugs prevents the breakdown of dopamine in the brain — a normal process that happens in everyone (Parkinson's or not) after dopamine does its job. MAO-B inhibitors stop this from happening as rapidly so that dopamine is present for longer periods of time. These drugs can be taken alone or coupled with levodopa or dopamine agonists to boost their actions. Potential side effects include flu-like symptoms, joint pain and blood pressure changes.

Examples of MAO-B inhibitors:

- » **Azilect (rasagiline):** pill
- » **Eldepryl (selegiline):** pill
- » **Zelapar (selegiline):** pill or dissolvable-in-mouth pill
- » **Xadago (safinamide):** pill

COMT Inhibitors

COMT inhibitors work solely to prevent the breakdown of levodopa and must be prescribed in conjunction with this drug. Since they allow levodopa to work longer, they are usually added if "off" times develop.

COMT inhibitors can cause harmless urine discoloration, loose stools or diarrhea. Tasmар (tolcapone) also may cause liver damage so regular laboratory monitoring is required while taking this medication.

Examples of COMT inhibitors:

- » **Comtan (entacapone):** pill
- » **Ongentys (opicapone):** pill
- » **Stalevo (levodopa/carbidopa and entacapone):** pill
- » **Tasmар (tolcapone):** pill

Amantadine

Amantadine works on the dopamine and glutamate brain chemical pathways to decrease motor symptoms, lessen "off" time or ease dyskinesia. There are three formulations of amantadine: one immediate-release (Amantadine) and two extended-release (Osmolex ER and Gocovri). Amantadine and Osmolex ER are FDA-approved to treat Parkinson's symptoms, such as slowness, stiffness and tremor. They may be prescribed alone in early PD for mild symptoms or with other drugs in mid or later disease. Gocovri is the first and only drug specifically indicated for dyskinesia. It's also approved to treat "off" time (when symptoms return), making it the only drug to ease both dyskinesia and "off" time. Common side effects are nausea, dizziness, insomnia, purple-red skin blotches, leg and foot swelling, blurred vision and hallucinations. People with kidney problems

may need to decrease their dosage.

Examples of amantadine:

- » **Amantadine immediate release:** pill or liquid
- » **Gocovri (amantadine extended-release):** pill
- » **Osmolex ER (amantadine extended release):** pill

Anticholinergics

This category of drugs works on the body's acetylcholine chemical system and restores the balance between acetylcholine and dopamine, which is disturbed in PD. Anticholinergics can be used alone or in combination with other Parkinson's drugs. They are commonly used to target tremor, especially in younger people, who are less susceptible to the drugs' side effects. These include blurred vision, dry mouth, constipation, problems with urination, short-term memory loss and confusion.

Examples of anticholinergics:

- » **Benzotropine:** pill
- » **Trihexyphenidyl:** pill

Adenosine Receptor Antagonist

These drugs block the brain chemical adenosine to boost the signaling of dopamine, which decreases in Parkinson's.

They are prescribed in addition to levodopa/carbidopa to lessen "off" time, when symptoms return between medication doses. Common side effects include dyskinesia, dizziness, constipation, nausea, hallucinations and insomnia.

Example of adenosine receptor antagonist:

- » **Nourianz (istradefylline):** pill

Focused Ultrasound

Focused ultrasound (FUS) is a non-invasive surgical procedure in which doctors use ultrasound beams to destroy brain cells that cause movement problems. FUS is currently FDA-approved for Parkinson's tremor that can't be controlled with medication but trials are evaluating whether this therapy also could ease dyskinesia and other symptoms, such as slowness, stiffness and "off" time. During the FUS procedure, a patient is awake; there is no general anesthesia or surgical incision. Typically, symptoms decrease immediately and, unlike with deep brain stimulation (DBS), there is no device, programming or adjustment following the surgery. But, unlike DBS, it is permanent and irreversible. And because of potential speech, swallowing or memory problems if done on both sides of the brain, FUS currently is only done on one side of the brain, which means it helps symptoms only on one side of the body. Other potential side effects include skin infection or rare bleeding.

Example of focused ultrasound therapy:

- » **Insightec Exablate Neuro**

MOTOR TREATMENTS AND ASSOCIATED COMPLICATIONS IN MIDDLE AND ADVANCING YEARS

Depending on which motor and non-motor symptoms are present, patients in the moderate to advancing years of the disease may be on complex and sometimes hard-to-manage medication regimens. Although treatment programs differ for each person, by this time nearly everyone

is on levodopa (sometimes with other Parkinson's medications) or has tried it.

Extended use of levodopa, in conjunction with longer duration of disease, can contribute to the development of motor complications.

Motor complications include "off" time and dyskinesia. "Off" is when symptoms return between doses — it can come on gradually, meaning a medication dose wears off before the next is due; in the morning, before the first dose is taken; or suddenly and unpredictably.

Dyskinesia, on the other hand, usually (but not always) occurs during “on” times when medication otherwise is managing symptoms well. (In some people, it might occur as levodopa is kicking in or wearing off.) Dyskinesia is uncontrolled, involuntary movement — often writhing or wriggling — that can involve any body part. It may look like swaying, head bobbing or fidgeting. Multiple options are available to treat motor complications and therapy is chosen based on an individual’s symptoms and current medications. To determine the best course of action, clinicians take several factors into account:

- » The average time it takes for a dose of levodopa to start working to decrease symptoms
- » The average length of time a levodopa dose works to control symptoms, and specifically if it lasts until the next scheduled dose is due
- » If any doses of levodopa take longer (or fail) to kick in
- » If Parkinson’s symptoms ever return suddenly and unpredictably
- » If dyskinesia is present and, if so, when.

Tracking this information can be difficult, but keeping a log of your symptoms and when you take medications may help guide discussions with your doctor. Conversations and medication adjustments also may go more smoothly if you can ensure you understand what is meant by “on” and “off” time as well as which of your symptoms is which (what’s tremor and what’s dyskinesia, for example). Ask your doctor about your symptoms or film them with your smartphone for review at your next appointment. Clinical trials are currently investigating wearable devices and smartphone apps that could make tracking symptoms and adjusting medications much easier for you and your doctor in the near future.

Options to address motor complications include:

- » **Changing the dosage and/or dosing schedule of levodopa.** The goal with levodopa is to take enough in each dose to control symptoms until the next dose is due without causing or worsening dyskinesia. It can be challenging to find this balance.
- » **Using an MAO-B inhibitor or an adenosine receptor antagonist.** To increase total daily “on” time, either of these types of drugs may be combined with levodopa and/or dopamine agonists.
- » **Taking a COMT inhibitor.** When levodopa wears off before the next dose is to be taken, a COMT inhibitor may be added to prolong its effect.
- » **Switching to a longer-acting formulation of levodopa.** Extended-release preparations of levodopa aim to keep a more steady level of medication in the system and thereby limit “off” times as well as dyskinesia. In some cases, switching from immediate- or controlled-release levodopa to Rytary (which combines carbidopa with both immediate- and extended-release levodopa in one capsule) might be considered. Another option may be Duopa, a levodopa/carbidopa gel that is infused continuously by an external pump into the small intestine through a surgically-placed tube.
- » **Adding amantadine.** If dyskinesia occurs, amantadine may be added. Gocovri (amantadine extended release) is the only drug FDA-approved to treat Parkinson’s dyskinesia as well as to treat both dyskinesia and “off” time. In some cases, doctors still use amantadine immediate release, which was the only form of amantadine available prior to Gocovri, to treat dyskinesia.
- » **Providing a rescue medication for “off” time.** Apokyn (injectable

apomorphine), Inbrija (inhaled levodopa) and Kynmobi (under-the-tongue apomorphine) are options to use as needed, in addition to other Parkinson’s medications, for “off” time. These medications may start to work in about 10 minutes (on average about 30) and last around an hour.

- » **Considering deep brain stimulation (DBS).** DBS is a surgical treatment that may be indicated for people whose symptoms still respond to levodopa but who have motor complications. Not everyone is a candidate, but those who are may see a substantial benefit in terms of symptom and medication reduction following the procedure.

At the current time, the FDA has approved DBS devices from three different manufacturers. While each device is unique, all DBS systems have the same basic components and work in a similar fashion. The differences in devices are not drastic, but they represent innovation and widen treatment options.

Examples of DBS devices:

- » **Abbott Infinity**
Abbott’s Infinity DBS was FDA-approved for Parkinson’s in 2016. The Infinity brain leads allow “directional stimulation,” which is a potentially increased ability to steer electrical stimulation toward symptoms and away from side effects. Abbott DBS operates with Apple iOS software and controllers (an iPad mini) for a possibly more familiar interface and easier programming experience. In 2021, Abbot developed a new technology (the first and only of its kind in the U.S.) that allows people with these devices to communicate with their clinician and receive DBS adjustments remotely, from their home or other location with WiFi or cellular access. People with Abbott DBS may have most MRI scans

safely when specific procedures are followed.

» Boston Scientific Vercise

Boston Scientific's Vercise became available for PD in Europe in 2012, and it gained FDA approval in 2017. Vercise's brain leads contain more points (eight vs. four in other systems) through which doctors can precisely deliver and control electrical stimulation. Vercise uses a rechargeable battery, which may last up to 25 years. This DBS device is safe for most MRI scanning as long as several conditions are met.

» Medtronic Activa

Medtronic's DBS was the first to be FDA-approved for PD, in 1997. Over

the past two decades, Medtronic has added newer systems with rechargeable and non-rechargeable batteries. Rechargeable batteries may last up to 15 years, but require regular recharges. Non-rechargeable devices last, on average, about three to five years, depending on an individual's settings. A person with Medtronic DBS can undergo most MRI scans safely when certain conditions are met.

» Medtronic Percept

Medtronic Percept was approved in Europe in early 2020 and gained FDA approval in June 2020. This first-of-its-kind device can sense and record an individual's unique brain signals. With this data, doctors may be able

to correlate patient symptoms with actual brain signals, which might eventually allow more precise DBS adjustments for possibly better symptom control and fewer side effects. Patients also can track their medications and symptoms in an electronic diary, which uses Samsung technology, so that they and their doctor can look for patterns between symptoms and brain signal changes. The battery lasts, on average, about five years, and is compatible with other Medtronic DBS leads. Percept is compatible with most MRI scans as long as safety conditions are met.

(Read more in the Deep Brain Stimulation section, page 36.)



NOT EVERYONE IS A CANDIDATE FOR DBS, BUT THOSE WHO ARE MAY SEE A SUBSTANTIAL BENEFIT IN TERMS OF SYMPTOM AND MEDICATION REDUCTION FOLLOWING THE PROCEDURE.

NON-MOTOR MEDICATIONS

Non-motor symptoms associated with Parkinson's can occur at any time but typically are more numerous and prominent in the middle and later years of disease. A number of treatments are available for management, a handful of which are specifically indicated for use in people with PD. The others, although FDA-approved, don't have this specific indication because they haven't been studied in large numbers of people with Parkinson's. Regardless, these drugs are widely prescribed in the general population of people without Parkinson's and are often used to treat non-motor symptoms in Parkinson's. Presently, the only therapies FDA-approved for non-motor symptoms in Parkinson's apply to hallucinations and delusions (psychosis), low blood pressure (orthostatic hypotension) and dementia.

Parkinson's Disease Psychosis: Nuplazid (pimavanserin)

Nuplazid received FDA approval in 2016 for the treatment of hallucinations and delusions associated with Parkinson's disease psychosis. (Read more in the section on Looking Ahead with Parkinson's Disease, page 29.) When symptoms of psychosis pose safety risks or impact a person's or their caregiver's quality of life, medication may be necessary. Nuplazid works on the brain's serotonin system to decrease symptoms of psychosis and also may improve nighttime sleep and daytime wakefulness. Because it does not block the dopamine system (as some other available antipsychotics do), it typically doesn't worsen motor symptoms. Nuplazid is a pill and its contents can be sprinkled on food

for people who have trouble swallowing. Common side effects of Nuplazid are leg swelling, nausea and confusion. Like most antipsychotics, Nuplazid carries a "black box" warning of increased risk of death when used in elderly people with dementia. As with any medication, this and other possible adverse effects need to be weighed carefully against potential benefits. In some situations, other antipsychotic medications indicated for treating mood and thought disorders (such as schizophrenia) are prescribed, including Clozaril (clozapine) or Seroquel (quetiapine). These drugs affect the dopamine and other brain chemical systems and may exacerbate Parkinson's motor symptoms. Before Nuplazid, these were among the only drug treatments available for PD psychosis and might still be an option in certain individuals.

Orthostatic Hypotension: Northera (droxidopa)

Northera was FDA-approved in 2014 for management of orthostatic hypotension — a decrease in blood pressure when changing positions (such as standing from sitting) that can cause dizziness, lightheadedness, fainting and, in Parkinson's, increased gait and balance disturbances. (See Sidebar, Non-motor Symptoms of Parkinson's disease, page 24.) When dietary and behavioral adjustments are insufficient, pharmacological management may be required. Northera is converted to norepinephrine, a body chemical that naturally raises blood pressure. Potential side effects include nausea, dizziness, headache and elevated blood pressure while sitting or lying ("supine hypertension"). If the latter

occurs, raising the head of the bed and/or taking blood pressure lowering medication at bedtime may be necessary. In certain cases, medications other than Northera, such as Florinef (fludrocortisone) or ProAmatine (midodrine), may be prescribed. Although these drugs aren't specifically indicated for use in PD, they were the only options available prior to Northera and may still be recommended for some people.

Parkinson's Disease Dementia: Exelon (rivastigmine)

Exelon was FDA-approved in 2006 for the management of mild to moderate dementia (significant memory and/or thinking impairment) associated with Parkinson's. (Learn more in the Looking Ahead with Parkinson's Disease section, page 28.) Exelon is an acetylcholinesterase inhibitor; it works by blocking an enzyme that breaks down acetylcholine, a brain chemical that supports memory and thinking abilities. Exelon may improve cognition, lessen associated behavioral changes (such as agitation or aggression), and delay the need for alternative living situations (such as nursing homes). Potential side effects include nausea, vomiting, diarrhea, decreased appetite, weight loss and increased tremor. Exelon is available in the form of a pill, oral solution and skin patch. In certain situations — if Exelon causes too many side effects, for example — other acetylcholinesterase inhibitors, such as Aricept (donepezil), which is indicated for Alzheimer's disease, may be prescribed instead.

COMPLEMENTARY AND ALTERNATIVE THERAPIES IN PARKINSON'S DISEASE

Many people with Parkinson's disease feel drawn to complementary and alternative medicine (CAM), which is an umbrella term for treatments that are not part of conventional, or Western, medicine. (Conventional medicine is defined as the usual practice of medicine by physicians with M.D. [medical doctor] or D.O. [doctor of osteopathic medicine] degrees and associated allied healthcare professionals, such as physical therapists.) "Complementary" typically refers to therapies that are used in conjunction with this mainstream medicine, whereas "alternative" indicates the use of certain therapies in place of standard medical treatments. CAM may involve "natural" therapies, which include supplements, herbs and vitamins; "mind-body practices," (acupuncture, yoga or music therapy); and "manual healing methods," such as massage or movement programs.

Few CAM therapies have been put through rigorous scientific study specific to Parkinson's and, as with all currently available pharmacological and surgical therapies, none have been shown to slow or stop disease progression. If you're interested, CAM may be worth exploring, but before taking action, it's prudent to consider any scientific evidence for or against the individual therapy, as well as potential benefits, side effects and costs. It's also important to discuss any CAM approaches you are considering with your healthcare provider to ensure they won't interact with or affect your current Parkinson's treatments.

While the list below is not comprehensive, it includes CAM therapies that may bring general benefit to people with Parkinson's disease, as well as treatments that claim effects on specific aspects of Parkinson's disease.

"Natural" Therapies of General Interest in Parkinson's Disease

"Natural" compounds, such as dietary supplements and vitamins, are regulated

by the U.S. Food and Drug Administration (FDA), but under a different set of guidelines from those used for prescription drugs. The FDA does not review or endorse the safety or effectiveness of these products. "Natural" therapies aren't necessarily safe or free from adverse effects, including interactions with prescription medications.

Some of the "natural" CAM therapies aimed at treating Parkinson's claim to boost mitochondria (the cell's energy producers); others say they limit inflammation. Many act as antioxidants to clear out free radicals — toxic substances formed from stresses like air pollution, sunlight, cigarette smoke and even the normal cellular processes involved in converting food to energy.

Supplements

Caffeine

In studies involving hundreds of people, greater caffeine consumption correlated with a decreased risk of Parkinson's disease. Correlation is not causation, though, and it's not clear if this is simply an association — people with Parkinson's disease consume less caffeine — or an indication that caffeine

might protect against PD. Caffeine blocks certain brain cell receptors in the basal ganglia (the part of the brain affected by PD) and in doing so, increases dopamine and decreases glutamate (another brain chemical). In one small trial, people with Parkinson's who took 200 mg of caffeine twice daily showed a mild improvement in motor symptoms. And, a survey of people with PD found that higher intake of coffee decreased the likelihood of dyskinesia (uncontrolled, involuntary movements). Caffeine is likely safe up to 200 mg twice daily but benefits of this are unknown. It's important to note that increasing caffeine intake could potentially exacerbate tremor, anxiety, sleep disturbances and urination.

Citicholine (CDP-choline)

This is a substance that may increase dopamine levels. It is closely related to choline, a nutrient that is also contained in acetylcholine — a body chemical that supports normal brain and nerve function. Oral and intravenous citicholine have been studied in Parkinson's. Small studies showed it might allow for a reduction in levodopa dosage and is relatively safe, though it may cause mild side effects, such as nausea, dizziness and fatigue.

Coenzyme Q10 (CoQ10)

This supplement is an antioxidant and a key factor in basic cell functioning and energy production. It became the focus of much research and patient interest in the 1990s and early 2000s, when claims were made that it held potential to slow or stop progression of Parkinson's. However, a large Phase III clinical study of CoQ10 in people with PD, sponsored by the NIH, concluded in 2011 after it failed to demonstrate any disease-modifying effect. Dosages of up to 2400 mg per day were found to be safe and well tolerated. Side effects include mild stomach upset, fatigue and dizziness. Many people with Parkinson's take CoQ10 and feel some benefit, but as with all supplements, this should be discussed with your medical provider. CoQ10 could potentially interact with prescription medications, including some blood thinners.

Creatine

Creatine is a substance that supports energy metabolism and acts as an antioxidant. A large trial of creatine 5 grams twice daily in people with Parkinson's was terminated early in 2013, due to lack of evidence of neuroprotection. Based on this trial, though, creatine was felt to be generally safe and well tolerated.

Glutathione

Glutathione is an antioxidant that also may support the function of mitochondria (the principal energy producers within brain and other cells). Brain glutathione levels are decreased in people with Parkinson's. Glutathione can be administered through several routes — oral, intravenous (IV) or intranasal (through the nose). Oral glutathione is poorly absorbed and may not reach the brain in sufficient quantities. Intravenous glutathione is expensive and has potential side effects (such as bleeding, infection and blood clots). Two small clinical trials of IV glutathione in PD did not prove efficacy and studies of intranasal glutathione did not show more benefit than placebo.

Inosine

Inosine is an antioxidant that is converted to urate in the body. In population-based studies, higher blood levels of urate were associated with a lower risk of Parkinson's disease. In previous clinical trials of other drugs for PD, higher urate levels were associated with less severity of disease over time. (These are associations, however, and not direct causations.) Unfortunately, a large, randomized, controlled, Phase III trial of inosine did not demonstrate benefit on Parkinson's progression. Potential risks of inosine include kidney stones, gout and high blood pressure.

Vitamins

Vitamin B1 (Thiamine)

Vitamin B1 helps cells use glucose (sugar) for energy. Some hypothesize that thiamine deficiency could increase brain cell stress, damage and loss. A few studies have found an association between low thiamine levels and Parkinson's disease, though these studies had limitations. Two small, open-label clinical trials of a high-dose injectable thiamine showed improvement on motor and non-motor symptoms. But the trials did not include a placebo group, so it is impossible to determine how much of the potential benefit may be from placebo effect.

Vitamin B6

This vitamin is necessary for many cellular processes, including the manufacturing of brain chemicals. It also decreases homocysteine, an amino acid that, when elevated, is thought to damage dopamine cells. One trial showed a correlation between higher intake of vitamin B6 in smokers and a lower risk of PD. Vitamin B6 can increase the rate of levodopa breakdown and therefore decrease its effectiveness.

Vitamin C (Ascorbic acid)

This is an antioxidant that can improve the production of dopamine. A small study of vitamin C in people with Parkinson's

who had motor fluctuations failed to demonstrate any benefit.

Vitamin D

This nutrient is important for general health and bone integrity. Vitamin D deficiency is common in the general population and among people with Parkinson's. Many physicians recommend vitamin D supplementation for bone health, but its potential benefits in PD are unknown.

Vitamin E

Alpha-tocopherol, the active component of vitamin E, is an antioxidant. A large study of high dosages of vitamin E in people with newly-diagnosed Parkinson's failed to show benefit over placebo in delaying disability or need for levodopa therapy. Vitamin E can increase risk of bleeding, so concurrent use of blood thinners is not recommended. It may also interfere with cholesterol-lowering drugs and chemotherapy agents.

Herbs

Medical Marijuana

Marijuana is derived from the plant *Cannabis sativa*, which contains about 100 different compounds referred to as cannabinoids. One is the major "psychoactive" component — Delta-9-tetrahydrocannabinol (THC) — which causes alterations in perception, mood and behavior. The second most common cannabinoid, cannabidiol (CBD), doesn't cause mind-altering effects. The ratio of THC to CBD and other cannabinoids varies from plant to plant and among the various formulations of medical marijuana.

The body naturally makes cannabinoids that bind to receptors throughout the brain. In doing so, they impact brain chemicals, including dopamine. Cannabinoids in marijuana may have antioxidant, anti-inflammatory and potentially neuroprotective effects. However, clinical studies into marijuana's effects on Parkinson's motor and non-motor symptoms have demonstrated

inconsistent outcomes. Some trials have reported benefit on non-motor symptoms (such as pain and sleep disturbances) as well as motor symptoms. Others, including studies on levodopa-induced dyskinesia, have produced mixed or negative results. (Of course, many anecdotal reports of benefit on both non-motor and motor symptoms exist as well.) Larger, well-designed trials using consistent formulations of marijuana are necessary to determine safety and efficacy in Parkinson's. At the time of this writing, a majority of states have legalized medical marijuana for use in Parkinson's. (Guidelines for use differ from state to state.) Medical marijuana should be used cautiously, balancing potential benefits against side effects, which could include nausea, dizziness, weakness, mood and behavioral changes, hallucinations and cognitive impairment.

Mucuna Pruriens

Mucuna Pruriens is an herbal supplement that contains levodopa — the most commonly prescribed therapy for Parkinson's disease, which is converted to dopamine in the brain. Unfortunately, the actual amount of levodopa contained in M. pruriens supplements is highly variable. The supplements are also impure, potentially containing trace amounts of serotonin (a brain chemical best known for its role in mood regulation), nicotine and probably several other compounds as well. A study of HP-200, a formulation of M. pruriens, in people with PD led to decreased disability, claims of safety and minor gastrointestinal side effects. Another trial compared M. pruriens to standard levodopa therapy, finding no difference in motor symptoms or motor complications between the two, but a potentially faster onset of action to symptom control with Mucuna pruriens. If the supplement is combined with standard levodopa, it could cause dyskinesia, and if taken on its own, it could cause inconsistent symptom control (because of unknown and varying levodopa amounts).

Traditional Chinese Herbal Medicines

These are sometimes used to treat non-motor symptoms associated with PD, such as fatigue, or sleep or gastrointestinal disturbances. Small studies have shown potential benefit on both non-motor and motor symptoms, but neither efficacy nor safety have been proven.

“Natural” Therapies for Parkinson's Non-motor Symptoms

DEPRESSION

Depression is a distinct condition that can be associated with Parkinson's disease, not solely a reaction to the diagnosis or life with a chronic disease. It occurs in many, but not all, people with PD. If untreated, it can aggravate both motor and non-motor symptoms of Parkinson's. Prescription drugs and/or counseling are available but, depending on the severity and an individual's preference, supplements are sometimes chosen instead. As with any therapy, these oral supplements and herbs should be reviewed with your healthcare provider before they are taken, especially since they could interact with certain prescription antidepressants and migraine medications.

5-hydroxytryptophan (5-HTP)

This is a precursor of serotonin, a brain chemical involved in mood and behavior. Studies comparing 5-HTP to standard antidepressants in the general population found some benefits on depression. It has not been studied specifically in people with PD.

S-adenosylmethionine (SAMe)

SAMe plays a role in many processes, including the production and breakdown of dopamine. Levodopa could decrease levels of SAMe, and SAMe could increase levodopa's breakdown, making it less effective. One small study of SAMe in people with Parkinson's showed that it was safe and decreased depressive symptoms.

St. John's Wort

This herb, which impacts brain chemicals including dopamine and serotonin, is sometimes taken for depression. However, study results have been conflicting and neither safety nor efficacy has been definitively proven. Potential side effects include psychosis, stomach upset, sunlight sensitivity and increased anxiety.

COGNITIVE IMPAIRMENT

Varying levels of cognitive (memory/thinking) disturbances can occur throughout the course of Parkinson's. They range from insignificant (detectable only on formal testing) to mild cognitive impairment to more severe (dementia).

Ginkgo biloba

Ginkgo is an herb that has antioxidant and anti-inflammatory properties and affects several brain chemical (serotonin, dopamine and norepinephrine) pathways. Clinical trials on ginkgo have provided inconsistent results, although a large placebo-controlled trial in adults with no or mild cognitive impairment showed that it failed to prevent cognitive changes. No large trials have been done in people with Parkinson's. Ginkgo is likely safe but should be combined cautiously with other medications, especially as it could interact with antidepressants and blood thinners.

Phosphatidylserine

This is a component of cells' outer membranes (protective barriers). It is purported to help with memory and possibly mood as well but scientific support is lacking. It should be used cautiously in conjunction with blood thinners.

Mind-Body Practices

Acupuncture

Often a component of traditional Chinese medicine, acupuncture uses needle insertion at various points in the body to redistribute “qi,” or energy, which is thought to be out of balance in the setting of disease. Small electrical pulses or bee venom can be applied with the needle to amplify the effects. Few

randomized or controlled trials have been performed on acupuncture in Parkinson's and outcomes on motor and non-motor (pain, fatigue, anxiety, etc.) symptoms have been inconsistent. In general, acupuncture appears safe and well tolerated. Anecdotally, many people report benefit.

Biofeedback

This technique helps a person achieve a greater awareness of the body and its natural reactions in order to gain control of any unwanted responses or symptoms. An MJFF-funded study applied biofeedback principles to successfully prevent and manage episodes of gait freezing in Parkinson's.

Music and Dance Therapy

Music can promote movement, expression and socialization and therefore impact an individual's physical, emotional and cognitive states. Studies have shown music can lead to positive brain chemical and structural changes. Several types of dance have demonstrated efficacy in the management of Parkinson's motor and non-motor symptoms.

Tai Chi and Yoga

Tai Chi is a traditional Chinese martial art that incorporates deep breathing,

relaxation and slow movements.

Studies in people with PD have shown that it's safe and potentially improves motor function and stability. Yoga is a mindfulness-based exercise that has, in some studies, demonstrated benefit on motor symptoms, balance and quality of life. Both tai chi and yoga could theoretically also lessen some non-motor symptoms. As with many forms of exercise, yoga styles and techniques differ and therefore, scientific study is challenging.

Manual Healing Methods

Manual therapy refers to treatments in which a practitioner uses his or her hands to provide therapy. In general, this seems safe and may positively impact mood and quality of life but objective data is limited.

Massage and Chiropractic Treatment

These practices manipulate the musculoskeletal system and realign the spine. Many people with Parkinson's report temporary improvements in stiffness and posture after massage and small observational studies have shown increases in walking speed as well. No controlled studies have been performed on chiropractic treatment for Parkinson's.

Movement Programs

These programs include the Bowen Technique, Trager Approach, Feldenkrais Method and Alexander Technique. None of these has been studied rigorously in PD. In the Bowen Technique, a practitioner subtly stimulates certain areas (muscles, tendons, ligaments or nerves), which is said to build a conversation between the nervous system and the rest of the body to improve symptoms. Trager therapists provide gentle movements, and individuals are taught complementary home exercises to increase relaxation, physical mobility and mental clarity. In the Feldenkrais Method, a practitioner uses gentle manual techniques to teach a person how to be more aware of and sense his or her movements to improve flexibility, coordination and posture. Teachers of the Alexander Technique gather details (through observation and light touch) about a person's movements and use this information to direct a person to couple thoughts and muscle activity in a purposeful manner. A relatively small study of people with Parkinson's who practiced the Alexander Technique showed improved disability and depression ratings.

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