







# Make Your Move

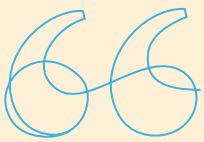
Exercise for brain health and life with Parkinson's

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

**Throughout this publication, keep an eye out for:**



Research highlights



Community member stories

## On the cover

*Clockwise from top left:*

**Karen Jaffe, MD**, a retired OB-GYN, founded InMotion, offering exercise classes to people with Parkinson's.

**Allen Dance**, diagnosed with REM sleep behavior disorder — a risk factor for Parkinson's — participates in research trials and enjoys biking.

**Bret Parker,** executive director of the New York City Bar Association, ran seven marathons on seven continents in seven days to raise funds for Parkinson's research.

See more photos of our Parkinson's community taking part in their favorite exercises throughout the pages of this guide.

## *What's the best exercise for Parkinson's?*

It's one of — if not the — most common questions we hear from people and families living with Parkinson's disease (PD). The answer is often, "The one you'll do!" And that's certainly true — research has proven the benefits of many types of exercise, and you want to find something you enjoy so you'll do it regularly.

But many people, understandably, want more specifics: *How hard should I work? How many times a week should I exercise? How do I work out with symptoms, as disease progresses, as I get older and have more aches and pains? How can I motivate my loved one with Parkinson's to move more?*

This resource answers these questions and more and offers practical tools and tips for exercise, wherever you are in life or life with Parkinson's. It was written by Parkinson's and exercise experts, informed by regular conversations with the Parkinson's community and guided by the insights of a small group of people living with PD. You'll find their stories — ranging from "exercise saved my life" to "exercise and I are frenemies" — and approaches to exercise throughout the book. Our hope is that you'll identify with their successes and struggles and feel inspired and empowered to start, restart or continue your own exercise journey.

Remember: Any type and amount of exercise can positively influence how you feel, how you manage PD and how you go through life. It's never too early or late to do something. And while you're the expert on yourself and your Parkinson's, you don't have to figure it out or go it alone. The PD, medical and exercise communities are here to support you every step of the way.

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# Community Contributors

We are grateful to members of The Michael J. Fox Foundation (MJFF) Patient Council, the PD Movers and the broad Parkinson's community who supported creation of this resource by sharing questions, experiences and feedback. Special thanks to:



## Jimmy Choi

Age 47; Diagnosed 2003
Bolingbrook, Illinois

Favorite exercise: single leg Romanian deadlift



## Hadley Ferguson

Age 46; Diagnosed 2010 with PD, 2013 with MSA
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Favorite exercise: stretching and manual manipulation; previously biking, Pilates, yoga and hiking



## Denise Coley

Age 72; Diagnosed 2018
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Favorite exercise: core, elliptical, aquatics



## Claudia Garrido-Revilla

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## Sandra Coplin

Age 66; Diagnosed 2016
North Haven, Connecticut

Favorite exercise: walking and moving with grandchildren



## Larry Gifford

Age 51; Diagnosed 2017
Vancouver, British Columbia

Favorite exercise: performing improv comedy

"There can be 'too much of a good thing.' Just as with medication, exercise should be prescribed, dosed and supervised. It's fun and beneficial, but it's useless if we get hurt. It only takes a second to twist an ankle or to fall and hurt a knee or hip. With Parkinson's, our recovery can be painful and slow. And I must insist: Everyone should get a bone scan. As we age, osteoporosis or osteopenia (thinning bones) might be around the corner."

Claudia Garrido-Revilla



### Lynn Hagerbrant

Age 67; Diagnosed 2010
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Favorite exercise: boxing, cycling, weightlifting



### Jim McNasby

Age 54; Diagnosed 2000
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Favorite exercise: a tie between biking and boxing



### Richard Huckabee

Age 63; Diagnosed 2013
Macedonia, Ohio

Favorite exercise: boxing; cycling a close second



### Kermit Smith

Age 68; Diagnosed 2015
Bronx, New York

Favorite exercise: weightlifting

# Moving through Daily Life

Let's be real. The activities of our lives and the areas in which we live may not encourage exercise. Desk jobs keep us sitting all day. TVs stream shows, one after another, without pause. Bike lanes may be few and far between. Online, rather than in-person, shopping is the norm. It's no wonder it can be tough to build movement into your day and make exercise a habit.

> "Everyone knows you need to exercise. So there can be a stigma if you don't. I'm still looking to come into exercise at the level I need to. I know the powers of exercise. I've seen it in other people. But I've yet to experience it myself. I've never gotten a 'high' from exercise. I've never been a big exercise person. We've been frenemies for a long time."
>
> Larry Gifford

But that doesn't mean you can't. There is a lot you can do, whatever your relationship with or approach to exercise. The first steps are figuring out what keeps you from moving more and learning all the ways you can exercise.

As you begin, let go of any guilt you may feel for not exercising as much as you know or think you should. Congratulate and be kind to yourself as you move forward. And set reasonable expectations for what you want to achieve in the weeks, months and years ahead. Any positive change is a good one and every step, however small, makes a difference.



*Larry Gifford looks at all aspects of living with PD, including exercise, through a podcast he co-hosts with his wife Rebecca, "When Life Gives You Parkinson's."*

# Is Exercise Just Moving More?

When you think of exercise, what comes to mind? Fancy gym equipment, expensive athletic clothing, marathon running or bodybuilding?

It can be all or none of that. Exercise is something all of us can do, anytime, anywhere. It can — and should — be enjoyable and available, no matter your health, fitness level or lifestyle. For some, exercise is outdoor cycling. For others, it's pickleball. Still others, it's water aerobics, boxing or dancing.

So is exercise just moving more? Yes and no. There's movement, or physical activity, and then there's exercise, which is a specific type of physical activity. Physical activity describes any movement throughout the day — around the house, at work, on errands, with hobbies and more. This could be cleaning your apartment, taking the stairs instead of the elevator, walking to a colleague's office, standing at your desk while you work, bowling, gardening, bird watching, golfing, mowing the lawn, playing with your kids or grandkids, or other low-impact, low-intensity activities. We all should try to move more and sit less. Regular movement helps mood, digestion, sleep and many other aspects of daily life.

But we need regular exercise, too, which brings more and bigger benefits. Exercise is structured, repetitive, goal-directed movement to maintain or improve well-being and physical fitness. It's planned, purposeful, focused movement that translates to a healthier heart and brain, less bothersome disease symptoms and the ability to move throughout the day — to rise from a low chair, get into and out of the car, walk up stairs, navigate the grocery store — with greater ease.



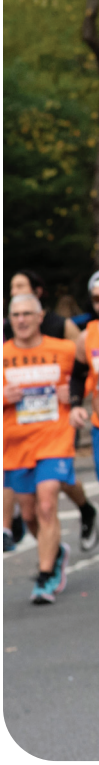

*Engaged PD* workbook; Teachers College, Columbia University, New York, New York and Cardiff University, Cardiff, Wales


RUN



# Remind Me Why I Should Exercise

Exercise is a powerful tool — one that we all have at our fingertips — for body, brain, and mental and emotional health. It has many potential benefits and few possible side effects. And it's widely available, low-cost and suitable for any age, medical condition or location. If exercise could be bottled, it'd sell better than any medication on the market.



## Exercise Protects the Brain

Tsukita, et al., *Neurology*, 2022

Using data from MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers examined the long-term effects of regular physical activity and exercise habits on the course of PD. Maintenance of regular physical activity levels and exercise habits was associated with a better clinical course of PD, with each type of physical activity having a different effect.

Most of us are familiar with the physical, or body, benefits of exercise: a strong heart, and strong bones and muscles. But exercise can also build a stronger brain! It does this by making growth factors, or "brain fertilizer," which lead to new brain cells, sturdier connections between cells, better blood flow and less inflammation. This is called neuroprotection, and it's how exercise could potentially delay, slow and even prevent disease like Parkinson's.

Exercise also encourages the brain to rewire or reorganize — to build new communication pathways that lessen or overcome disease symptoms or damage. It's like finding a less-traveled detour that bypasses a blocked road while driving. An example is regaining movement after a stroke. This is called neuroplasticity, and it's another way exercise might slow Parkinson's progression. That's something no medication or other treatment has yet been proven to do, although research in this area is active and promising.




*A physician and avid marathoner, Joyce Chu, MD, raises money and awareness for PD.*

> "When I learned that exercise was the best option for slowing the disease progression, it was like a blessing. I now had something that gave me control of my destiny and that is an opportunity I won't pass up."
>
> Parkinson's community member

Exercise has more immediate and noticeable benefits for Parkinson's, too. It can:

+ Ease motor and non-motor symptoms, like constipation, sleep changes or mood troubles;
+ Lessen balance changes or falls, which medications and surgeries can't yet fully treat; and
+ Help medication work better by helping the brain use dopamine (the chemical that decreases in PD) better.

That may be motivation enough to get or stay active. But there's even more reason. Exercise supports mental, emotional and spiritual well-being — a key, but sometimes overlooked, part of overall health. As Brock Chisholm, MD, psychiatrist and initial Director-General of the World Health Organization, said, "Without mental health, there can be no true physical health." Physical and mental health go hand-in-hand. How we feel impacts how we behave, move, sleep and manage stress, and vice versa. Feeling well

## Exercise Changes the Brain

Johansson, et al., *Annals of Neurology*, 2021

In the Park-in-Shape trial, people with PD were randomly assigned to either an aerobic exercise (stationary bike at home) or a stretching program for six months. Aerobic exercise, but not stretching, increased brain pathways (functional connectivity) in certain regions and reduced brain shrinkage (atrophy). Aerobic exercise also improved memory and thinking (cognitive) performance.




*Businessman and PD advocate Gary Rafaloff enjoys a game of pickleball.*

## Exercise Can Ease Non-Motor Symptoms

Amara & Memon, *Clinical Therapeutics*, 2018

A 2018 review paper outlined the potential for exercise to impact a range of non-motor symptoms in PD, including changes in the nervous system leading to blood pressure, urine and gut symptoms (autonomic dysfunction), memory and thinking (cognitive) impairment and sleep disorders. The authors note that these symptoms have not been studied as well as motor symptoms and more research is needed to understand the mechanisms underlying exercise-induced changes and the best exercise interventions for certain symptoms.

emotionally might mean we choose a walk in the park with a friend over snacking solo in front of the TV. And starting the morning with movement might lead to a healthier breakfast and positive outlook on the day.

Exercise is one of the best things you can do for yourself, whether you live with Parkinson's or love someone who does. The earlier you start, the better. But it's never too late or too little — any effort makes a difference.

# Exercise: One Ingredient in a Healthy Mix for Life

Movement and exercise are key to living as well as possible, whether you have Parkinson's or not. But there are other, just as important, factors. These include:

+ **What you eat:**
  Eating mostly whole, unprocessed foods — fruits, vegetables, whole grains, legumes and beans — can boost mood and energy, improve digestion and enhance overall well-being. And the better you feel, the more likely you are to move.

+ **How you connect:**
  Meaningful relationships are good for the heart, brain and soul. The more we engage with others, the more we exercise our brains and move our bodies. This can be challenging around the time of diagnosis or later in disease, but there are ways to connect and limit loneliness, including one-to-one or virtual visits.

+ **How you sleep:**
  Aim for seven to nine hours each night, knowing you may need a little more or less, and that Parkinson's and other conditions may impact sleep. Invite good sleep by moving throughout the day, eating healthy foods and getting natural light exposure.

+ **How you manage stress:**
  Stress can temporarily worsen PD symptoms, interfere with sleep and affect food choices, which can all negatively influence exercise. You can't get rid of stress, but you can limit its impact. Exercise is one way, but there are others — practicing mindfulness, journaling, creating art, listening to music or talking with a counselor or confidant.




*Richard Huckabee, left, and Michael Fitts find connecting over a workout at the gym helps them live well with Parkinson's.*

+ **Whether you limit risky substances:**
  Be as kind to your body as you can. Give it good fuel — healthy food and lots of water — and avoid harmful substances like cigarettes, too much alcohol (more than one drink a day for women or two for men) and, where possible, pesticides and other toxic chemicals.



*Abandoning your fear of the future is key to begin living your present, says Soania Mathur, MD, a physician who lives with PD.*



# What, Exactly, Should I Do?

Now that you're (hopefully!) enthused about exercise, you may be thinking, *That's great information, but how do I put it into practice?* In this section, you'll find answers to that question and much more — recommendations on what exercises to do and how often, how hard to work and how to measure how hard you work, and how to set and meet exercise goals.



## As Little as 10 Minutes of Exercise Helps

Saint-Maurice, et al.,
*JAMA Internal Medicine*, 2022

In an observational study among U.S. adults with and without PD, researchers found that increasing moderate to vigorous activity by just 10 minutes a day from any level could have significant benefit in terms of mortality. These results were observed for men and women and people of different racial backgrounds.

## More than Cardio

When it comes to exercise, many of us think mainly of "cardio" or aerobic exercise, like running or using the elliptical. But there are other types of exercise that are just as important. These include strength, flexibility and balance. Each works different body systems and supports different functions, like standing or keeping balance, to keep us moving through daily life.

This amount of exercise — and the time to do it — may seem overwhelming. But there are ways to fit more exercise in less time. Some activities, such as non-contact boxing and dancing, involve multiple types of exercise. So one class could count as both aerobic and balance exercise. And you can combine activities, doing jumping jacks (aerobics) between weightlifting (strength) sets, for example. A physical and/or occupational therapist can help you build a plan that fits the time you have.

## Know the Different Types of Exercise

| | Aerobic | Strength | Flexibility | Balance |
|---|---|---|---|---|
| **What does it do?** | Supports heart, lung, brain and whole-body health | Builds muscle and strengthens bones | Allows joints and muscles to move more freely | Boosts stability |
| **What are the benefits?** | Better health and well-being, mood, memory, digestion, etc. | Improved movement and overall health, less risk of breaking bones | Healthier joints, less pain and injury risk | Smoother walking and less falling |
| **What might it look like?** | + Brisk walking<br>+ Nordic walking, also called Urban Poling<br>+ Hiking<br>+ Jogging or running<br>+ Biking<br>+ Swimming or water aerobics<br>+ Martial arts<br>+ Skiing<br>+ Canoeing<br>+ Skating<br>+ Playing basketball, tennis, pickleball or other sports | + Lifting weights<br>+ Working with resistance bands<br>+ Bodyweight exercises, like squats, push-ups or sit-ups<br>+ Heavy gardening, with digging and shoveling | + Yoga<br>+ Pilates<br>+ Targeted stretching of upper body (neck, back, chest, trunk, arms)<br>+ Targeted stretching of lower body (hips, knees, ankles, feet) | + Dance<br>+ Tai chi<br>+ Non-contact boxing<br>+ Ping-pong<br>+ Kayaking<br>+ Yoga<br>+ Pilates |
| **How often should I do this?*** | At least 3 days per week<br><br>30 to 40 minutes per session<br><br>Moderate to vigorous intensity (See page 20) | At least 2 to 3 non-consecutive days per week<br><br>30 to 60 minutes per session | At least 2 to 3 days per week (daily, if possible)<br><br>For major muscle groups, hold 30 seconds and repeat 2 times | At least 2 to 3 times per week (the more, the better)<br><br>30 to 60 minutes per session |

*Adapted from the American Physical Therapy Association and the American College of Sports Medicine exercise guidelines for Parkinson's.

"Parkinson's doesn't take a day off and neither should we. I have a lot of issues with my shoulders and upper back. And these are worse when I wake up. But all of my symptoms are far less when I do aerobic exercise — when I get my heart rate up and keep it there. Still, I had to find a balance. I tended to do more aerobics and not enough other exercise. Through community and programs, I learned to build in everything else."

Lynn Hagerbrant



*Retired nurse Lynn Hagerbrant, with her trainer Ray Fructuoso, incorporates exercise into living with PD and being a care provider.*

## Exercise May Slow Disease Progression

Schenkman, et al., *JAMA Neurology*, 2018

This study provided preliminary evidence that high-intensity (80 to 85 percent of max heart rate) treadmill exercise is better than moderate intensity (60 to 65 percent of max heart rate) treadmill exercise at slowing disease progression. At the time of publication, an ongoing large-scale trial (SPARX 3) aims to determine if high-intensity treadmill exercise produces meaningful clinical benefits in people with early PD who are not yet taking medication.

## Make the Most of Exercise in the Least Time

Start your exercise routine with flexibility as a warm-up. Then consider including the three major types of exercise (aerobic, strength, balance), which are depicted in primary colors (red, blue and yellow respectively).

Blended exercise programs (secondary colors) combine different types of exercise to help you be more efficient with your personalized exercise routine. You can add cognitive dual tasking for additional benefit. This is doing two or more tasks, like walking and talking, performing a balance activity while counting backwards, or doing simple math while running. Talk with your physical therapist or other exercise professional to see if this is advised and how you can do this safely.




Courtesy of the Academy of Neurologic Physical Therapy

## Physical Activity Can Improve Life Quality

Rafferty, et al., *Journal of Parkinson's Disease*, 2017

Using data from the National Parkinson Foundation Quality Improvement Initiative (NPF-QII), researchers found that increasing physical activity (general movement throughout the day, not specific to exercise) to at least two and a half hours (150 minutes) a week can slow decline in quality of life with PD. The results from this and other studies were used to develop the American College of Sports Medicine's guidelines for exercise in PD.



*Parkinson's disease advocates Denise Coley, who lives with PD, and her husband Bernard Coley approach PD through engagement and an active lifestyle.*

## How hard to work: Learn to measure intensity

How hard you work during exercise is the intensity. There are three levels — low, moderate and vigorous. For most benefit, aim for moderate to vigorous, remembering that higher intensity may not always be possible and any movement is good. The best intensity for you depends on your health, fitness and exercise goals.

Let's practice. Say you are 75 years old, not taking blood pressure medication and have a resting heart rate of 70 beats per minute. Your:

+ Maximum heart rate is 145. This is 220 minus your age (75).
+ Heart rate reserve is 75. This is maximum heart rate (145) minus resting heart rate (70).
+ Target heart rate range for moderate to vigorous exercise is 115 to 134. This is [heart rate reserve x desired exercise intensity] + resting heart rate, with 60 percent and 85 percent as lower and upper limits of desired intensity for moderate to vigorous exercise. That's [75 x 0.6] + 70 = 115 and [75 x 0.85] + 70 = 134.

## Be clear on what you want to get out of exercise: Set goals

A goal is something you want to achieve through exercise. It could be specific to the exercise itself — *I want to ride my bike three times a week* or *I'd like to run for 40 minutes without stopping*. Or it could be related to

## Choose a Tool

There are several ways to measure exercise intensity. All work, so pick the best for you.

| | **Talk Test** | **Rating Scale (Borg CR-10)** | **Heart Rate Monitoring** |
|---|---|---|---|
| **What is it?** | Talk or sing to measure effort | Rate your effort on a scale from 1 (lightest) to 10 (hardest) | Measure heart rate, aiming for your personal target range |
| **Low intensity** | Can talk and sing | 1-2 | <59% of maximum heart rate (MHR) (see page 20) |
| **Moderate intensity** | Can talk but not sing | 3-6 | 60 to 74% of MHR |
| **Vigorous intensity** | Cannot talk or sing | 7-10 | 75 to 85% of MHR |
| **Pros** | No equipment needed | No equipment needed | Objective (measurable) |
| **Cons** | Subjective (based on how you feel) | Subjective | Need equipment (e.g., smartwatch) and target heart rate calculation |



"Listen to your body! Do you feel pain somewhere? Before and after knee replacements, I was more active and regularly adjusted my exercise schedule due to how my knee felt. My favorite exercises are the elliptical, tai chi and aquatics. My PT introduced me to aquatics, and I love it. Look to see what you can do at that moment in time and realize that every day is different. Some days, you might change your exercise schedule, but always remember the importance of exercise."

Denise Coley

## For Heart Rate, Know the Math

Here's what different heart rate measures mean and how to calculate yours.

| | Maximum Heart Rate (MHR) | Resting Heart Rate (RHR) | Heart Rate Reserve (HRR) | Target Heart Rate |
|---|---|---|---|---|
| **What is it?** | Highest number of beats per minute your heart can reach during exercise | Number of times your heart beats each minute when not exercising | Difference between maximum heart rate and resting heart rate | Your desired exercise intensity, represented by a specific heart rate |
| **How do I calculate or measure it?** | Quick Estimation<br>220 - age<br>OR<br>More Accurate<br>206.9 - (0.67 x age) | Measure with a heart rate monitor, such as a smartwatch or exercise equipment, if available | Maximum heart rate (MHR) – resting heart rate (RHR) | [Heart rate reserve (HRR) x desired exercise intensity*] + resting heart rate (RHR) |
| **What if I'm taking a blood pressure medication that lowers heart rate (a beta blocker)?** | These medications limit how high your heart rate can go with exercise (this is called heart rate blunting)<br>Use this formula for MHR: 164 - (0.7 x age) | May remain the same as before medication or decrease slightly | As with MHR, heart rate reserve will be lower with these medications | Your target heart rate will be lower, but you can still aim to achieve a beneficial target range (e.g., 60 to 85% of MHR) |
| **Where can I find an online calculator?** | Ask your physical therapist or an exercise professional to direct you to an online calculator. | Not applicable | Ask your physical therapist or an exercise professional to direct you to an online calculator. | Ask your physical therapist or an exercise professional to direct you to an online calculator. |

*Desired exercise intensity is how hard you want to work. For moderate to vigorous exercise, that's 60 to 85 percent of your maximum heart rate.

life with Parkinson's — *I'd like to get in and out of the car more easily* or *I want to feel more confident walking outside my home.*

Write down three to four goals and make each SMART:

+ **Specific:** detailed — which activity, how long, how often, etc.
  Example: *I'll ride my stationary bike for 30 minutes at moderate intensity twice this week before I go to work.*

+ **Measurable:** defined, trackable
  Example: *I will go for a 10-minute walk with my spouse after dinner three nights a week.*

+ **Attainable:** realistic; challenging but possible
  Example: *I am going to join a gym and take an afternoon spinning class once a week.*

+ **Relevant:** matters to you
  Example: *I'll walk to the mailbox every morning without my cane.*

+ **Time-bound:** within a set timeframe
  Example: *I will go to boxing class every Monday at 10 a.m. for the next month.*



*For Richard Huckabee, cycling with his wife Angela is a way to incorporate exercise with relaxation.*

For each goal, ask: *How confident am I, on a scale from one to 10 (10 being very confident), that I will be successful?* If you answer five or less, reflect on why you don't feel more confident. Are there barriers you need to work around or is the goal too hard right now? Make sure each goal is "just right" — something that stretches you, but is within reach. As you achieve initial goals, you can set new, more challenging ones. And remember, goals to maintain — such as continuing your current fitness routine — can be important, too.

A physical and/or occupational therapist can help you set goals, build a plan to meet them, track progress and adjust along the way.

"Exercise saved my life. I didn't exercise before Parkinson's. I was 50 pounds heavier than I am now. At diagnosis, my doctor sent me to a physical therapist. And they invited me to be part of a drumming and dancing research study. I met a great group of people, a community I'm still in touch with. And that was a big part of getting the exercise, help and team I needed. My PT helped me walk without a cane. My occupational therapist taught me to drive again. My sports therapist taught me about injuries and how to let them heal."

Richard Huckabee



*Former executive and innovator Bill Bucklew inspires the PD community by creating ultra-endurance events and relay teams with people with Parkinson's.*



# What if Life or Parkinson's Gets in the Way?

If it hasn't already, it will! Life, and life with Parkinson's, can throw curveballs that make exercise feel like the last thing you can or want to do. But with planning, creativity and determination, you can work around what life throws your way to put your best effort into exercise and get the most benefit out of it.

Make sure to keep in regular conversation with your doctor — not just about exercise but, more importantly, about your PD and any symptoms that make exercise tougher. Don't assume everything is Parkinson's (maybe that nagging pain is a new injury, for example) or that nothing can be done. Together, you and your doctor can figure out medication adjustments and non-medication strategies to keep you moving as much as possible.

## Make the Most of Exercise

Whether you're an exercise newbie or veteran, consider these tips for putting your best foot forward with every workout.

+ **Timing is everything.** Work out when you have the most energy and your medication works best. For many, levodopa kicks in after about 30 to 60 minutes, but this varies. Any time of day is okay for working out, but limit high-intensity exercise after 7 p.m., as this can interfere with sleep. If you want to move before bed, try something lighter and more relaxing, like stretching or yoga.

+ **Start fresh each day.** We all have good days and not-so-good days, especially with Parkinson's. Be as active as you can but give yourself a break when needed. Not every day will include a workout, even if you plan one. Sometimes the best workout is the one you don't do. Recommit to exercise each day and celebrate small wins — starting a workout, making it halfway through or walking your first full mile without stopping.

+ **Prescription for progress.** If symptoms increase during exercise, or it feels like you "go through" medication more quickly, ask your doctor if medication changes might help. Some people benefit from taking a higher dose just prior to working out or having as-needed medication on hand during activity.

+ **Wet your whistle.** Drink at least six to eight large glasses of water a day. And drink more during and after exercise. Carry a water bottle (in your hand, waist belt or shoulder strap) or work out near public drinking foundations. If you sweat a lot or have low blood pressure, ask your doctor whether salt supplements or electrolyte drinks would help, too.

+ **Test and learn.** Experiment with various exercises and ways of exercising. Try working out alone, with a friend or in a group. Take a class for older adults or people living with PD. Join a walk/run, cycling or other event for the Parkinson's community. (See page 64.) See if you prefer classes in-person or online, live or on-demand. Consider participating in research on exercise, too. (Check for ongoing studies at foxtrialfinder.org.)

+ **Take it easy.** Follow the mantra, "Start low and go slow." If you haven't been active, begin with short sessions a few days per week and gradually increase. (A general rule is to increase time or distance no more than 10 percent per week.) And ease in and out of each workout with a five- to 15-minute warm-up and cool down. This gives your body and mind time




*Joe Drake achieved his goal of running the Chicago Marathon in 2023.*

to transition and is extra important if you have low blood pressure or balance problems.

+ **Use it or lose it.** Consistency is key. It can take a few weeks to see benefits, but only days for them to disappear if you stop regular exercise. This is why it's so important to find something you enjoy and will stick with.

+ **Safety first.** Especially when exercising alone or outdoors, tell someone where you're going and how long you plan to be out. Update emergency contacts in your telephone and/or wear an alert bracelet listing this information and your medical conditions.

+ **Tune in to your body.** This is how you find the right activities and effort levels. Some people have joint, muscle or back problems that can cause pain or discomfort, particularly with exercise. Consult a physical therapist, who can help you adapt exercise to prevent or limit pain.

# Work through Common Challenges

People with Parkinson's often share, and research confirms, that there are many barriers to starting or sticking with exercise. These include limited time or resources, access to experts, lack of knowledge about exercise, PD symptoms and others.

Here, we discuss common stumbling blocks and suggest strategies for each. But always speak with your personal care team, especially if you have new or worsening symptoms during or after exercise.

## Limited time: "I'm too busy to exercise."

Not having enough time is one of the main reasons people say they do not exercise. Exercise can feel like yet another "to-do" on top of working or volunteering, caring for or spending time with family, or managing doctor appointments, pharmacy trips and more.

### Strategies

+ **Pencil it in.** Make exercise a priority. Schedule an appointment in your calendar or datebook for exercise, just like you do a doctor's appointment or work meeting. And set an alarm on your calendar, watch or phone to remind you.

+ **First things first.** Exercise early in the day, if possible. This gets exercise "out of the way," before fatigue, a longer-than-planned day or other unexpected hiccups interfere with plans.

+ **Make time.** What can shift to allow time for exercise? Might you get up a little earlier, walk or bike to work, or ask your partner or friend to drop off or pick up your children a few days a week?

+ **Do more in less time.** Do flexibility exercises while listening to the radio or during TV commercials. Head to the gym on the way to or from work or during your lunch hour. Meet a friend for exercise class before grabbing coffee. Take the stairs, stand at your desk or walk during meetings.

## Limited resources: "I don't live near a gym and that's too expensive anyway."

Exercise can be done anywhere — even indoors, in small spaces and without any fancy equipment.

### Strategies

+ **Move your body.** You can get plenty of exercise with just your body — no weights or equipment needed! Try sit-ups, push-ups, squats or jumping jacks, which are both strength and aerobic exercise in one.

+ **Use your imagination.** Common household items can serve as weights. These include things like milk jugs, water bottles or cans of soup. Go up and down stairs or do laps around the house or block for cardio.

+ **Go low- or no-cost.** You don't have to pay for a gym membership. Look for exercise through:

  – Community, wellness or senior centers

- Adult day programs
  Often tailored to people with memory or thinking (cognitive) changes or other significant symptoms who can benefit from supervised exercise and social engagement.
- Silver Sneakers
  Available to people with certain Medicare plans; offers in-person and online classes, workshops and more
- Local parks
- Religious facilities
- Public libraries
- Fitness stores or studios
- Veterans Affairs (VA) hospitals
- Online programs, smartphone apps, videos or DVDs, or on-demand streaming programs

For Parkinson's-specific classes, see page 64. And ask your doctor, physical or occupational therapist and other community members for recommendations.

## Unfamiliarity: "I am not sure I can exercise correctly."

Exercise can be intimidating. Whether it's trying a new exercise or class, using equipment, or navigating the gym, it may be a little scary. *Will I look silly? What if I can't do it? What if I hurt myself?* Remember, everybody was once new to exercise. And there are people and tools to help you get started and stay safe.

### Strategies

+ **Ask the experts.** Work with an exercise professional if you're exercising for the first time ever, the first time with Parkinson's or the first time with a new symptom. Just a few sessions can get you moving in the right direction. (See page 64.)
+ **Practice makes perfect.** For new or more difficult exercises, have an expert observe and give feedback until you're comfortable on your own. Begin with a few exercises you feel confident you can master. Gradually take on more and more challenging activities as you gain knowledge, strength and trust in yourself.
+ **Partner up.** Ask another person, such as a friend, spouse or carer, to join physical or occupational therapy appointments and then watch you do "homework" exercises on your own or, better yet, do them with you.



"I think of exercise as more important than taking my medicine. I exercise seven to 10 hours a week. After about 18 years with PD, I got deep brain stimulation (DBS), which allowed me to physically go back to year three or four of my PD, when symptoms were more minor, and exercise became easier. On the downside, I may have exercised too much. I need a hip replacement. I also have a bad shoulder and knee. I call it the triangle of pain. So I try to do things like biking, where I don't have to transfer my weight too much. And I wonder, how do I get benefits of exercise without doing damage?"

Jim McNasby

"Coming into recovery in 1999, I had a sponsor who got me to go to the gym. Recovery taught me to deal with life in three ways — mentally, physically and spiritually — to learn to reinvent myself because life is always changing. I do affirmations: I tell myself, I am strong. I am physically fit. In 2002, I tore my right rotator cuff, and later, I tore the left. I had surgery to repair both and I went back to weightlifting, getting up to benching 225 lbs. Then I tore my left rotator cuff again but never got it repaired. In 2015, I started having more pain and I couldn't weightlift. I switched to more cardio and tai chi. I've been managing with injections and physical therapy because I don't want surgery. Life has taught me one thing: you get out of it what you put into it. Physically I am not giving in."

Kermit Smith

+ **Make it a group effort.** Join a class, club or gym where there is help available. This could be someone who can show you how to use a machine, confirm technique is correct or provide hands-on instruction. And ask questions — learn how certain exercises work and why it's important to do them.

## Pain or injuries: "Will exercise make my pain or injury worse?"

Pain can, for some people, be part of Parkinson's disease. Pain can be from the disease itself or from a symptom, like stiffness or muscle cramping (dystonia). People with PD (and older people, with or without PD) also are more prone to back problems or pain as well as muscle strains or tears, tendon inflammation (tendonitis) or ligament strains. These are known as "musculoskeletal" issues. They may be more common in PD because of motor symptoms or walking changes that put extra stress or strain on certain areas. Musculoskeletal problems cause different types of pain, such as shoulder stiffness, hip or knee aching, or lower back pain. Pain can make exercise more difficult, and injury requires an exercise break or modification. Consult a physical therapist, who can provide exercises, tools and workarounds as well as ways to prevent pain and injury.

### Strategies

+ **Motion is lotion.** Movement helps lubricate joints, and this is essential for moving more easily and healing injuries. Blood flow, which increases with aerobic exercise, can help heal an injury and ease pain. The key is finding the right type and amount of movement for you and your symptoms.

+ **Warm up or cool down.** Ice and heat are tools to ease pain and speed recovery. Ice lessens pain and limits inflammation. Heat increases blood flow to support

healing. If you have a sudden injury, like an ankle sprain, ice is the answer. If you have a sore muscle, a warm shower or hot pack before or after exercise might help. Ask your physical therapist or exercise advisor which method to use when.

+ **Keep a can-do attitude.** Focus on what you can do, instead of what you can't. If your shoulder is injured, do lower body or core exercises — squats or sit-ups instead of push-ups or planks. If your foot or ankle bothers you, do upper body exercises — rowing rather than walking. Modify weightlifting, too, where needed, switching from dumbbells or kettlebells to resistance bands or bodyweight only.

## Lack of motivation: "I know I should exercise, but I don't have the get-up-and-go."

It is natural for everyone — even the most enthusiastic exerciser — to sometimes feel unmotivated. We might get bored or feel down, depressed or low on energy. But some people with PD experience a more constant and significant lack of motivation (apathy). This can extend to exercise, hobbies and even daily activities. Apathy can be tough to work through. And it can be tough for loved ones, too, who may feel powerless to help. Exercise is one way to lessen apathy, but it can, understandably, be hard to do.

### Strategies

+ **What moves you.** Find your motivation. That might seem impossible when, by definition, apathy takes it away. But there are many sources of motivation, both within and outside you. Outside motivation could be encouraging comments to your social media posts about exercise, a T-shirt or medal upon finishing a walk, or improvements in fitness or health. Internal motivation could come from enjoying or getting lost in activity or feeling a sense of accomplishment. While walking in nature, for example, you might soak up "alone" time, disconnect from email and texts and forget to-dos or worries.

+ **All fun and games.** Pick something you think you'll like or that you once enjoyed, even as a child. Try different activities to keep your body guessing and your brain interested. Ask friends and family to join or support you.

+ **Small steps to big goals.** Goal setting is good for apathy. Start with small, measurable targets, such as walking 10 minutes every other morning for one week. (See page 20.) Tell others your goals so they can support you. Record activity so you can see progress.

+ **Mood music.** Create a playlist of upbeat, energizing music that makes you want to move. Or download your favorite television show or podcast to enjoy only while exercising.

> "Through my insurance, I get $10 on a credit card every month I meet my step goal. That motivates me to get steps in. Whatever works for you, use it!"
>
> Richard Huckabee




*Allen Dance, enjoying a day with his exercise of choice: cycling.*

+ **Get in the habit.** Pair exercise with an activity you do every day so it naturally becomes a habit. Do balance exercises right after brushing your teeth. Jump on your bike after drinking coffee in the morning. Stretch as soon as you get home from work.

## Mood changes: "I just don't feel like exercising."

Many people, both with and without Parkinson's, feel down (depression) or overly worried (anxiety). These mood changes can, in PD, be symptoms of disease or natural emotional responses to living with it. While exercise (as well as medication and mental health therapy) can help, it can be harder to work out if you live with mood changes.

### Strategies

+ **Five-minute rule.** Tell yourself you'll work out for five minutes. If you want to stop then, you can. Most of the time you'll keep going once you've started.

+ **Match the mood.** Different activities work for different moods and times of day. Vary exercises and timing to see what works best. A group or intense workout might lift your spirits. Outdoor activities, which increase sun exposure, can boost mood and help sleep. Slower activities, like yoga, tai chi, Pilates or pool exercise, may be calming.

+ **Take work out of working out.** Set out your exercise clothes and shoes the night before, keep a glass of water on your nightstand so you can hydrate upon waking, or plan to meet a friend so it's harder to make excuses. Start and end each session with a few deep breaths or moments of meditation to set the intention for exercise and tone for the day.

## Fatigue: "I'm too tired to exercise."

Some people with PD feel very tired much of the time. This can happen for many reasons, including trouble sleeping, low blood pressure, medication side effects, vitamin deficiencies or mood changes. Fatigue can also be a symptom of Parkinson's. Researchers don't fully understand why, but living with disease might make your body work harder and use more energy.

Parkinson's fatigue is different than feeling tired from time to time. Breaks or naps may not help. It can take longer to do things and you might tire from previously easy tasks, like getting dressed or making a sandwich. Fatigue can make exercise seem impossible. But regular exercise, along with getting the best sleep you can, staying hydrated and eating well, can ease fatigue and increase energy.

### Strategies

+ **Be picky.** Which exercise is most important to meeting your goals? Prioritize that. Do it when you have the most energy and earlier in the day or week, so you don't miss it.

+ **Save your stamina.** Tailor the type and amount of exercise to how much energy you have. If energy is low, cut back temporarily. For example, try 15 to 20 minutes of aerobic exercise three days a week instead of 30 minutes five days a week. See if that helps and then gradually build back up.

+ **"Snack" on exercise.** Do short bits of exercise — 30 seconds to five minutes — throughout the day. Whenever you've got a break, sit and stand a couple times, climb a flight of stairs, walk around your living room or throw a few boxing punches. Bring more movement into everyday activities — stretch during TV commercials, walk while talking on the telephone or listening to a podcast, or stand from your couch or desk once an hour.

## Low blood pressure: "I feel dizzy or lightheaded when moving."

Low blood pressure, or orthostatic hypotension, can happen in Parkinson's, because of the disease or medications to treat it. Orthostatic hypotension is a persistent drop in blood pressure when changing

"Before I was diagnosed, I didn't do a lot of exercise. I sat at a desk for hours and hours. One of my first symptoms with PD was extreme fatigue — I never imagined someone could feel that amount of fatigue! My doctor recommended seeing a physical therapist, who suggested walking to build strength in my legs. I took to that the most. I bought a Fitbit and set goals to increase my steps. I notice a drastic difference in how I feel today versus a few years ago. I don't need the Fitbit anymore. I watch when my symptoms seem to come on — I might have more imbalance in the evenings — and I manage my day based on my symptoms. I also have two young grandchildren who provide all the activity I need!"

Sandra Coplin

positions, like standing from sitting or sitting up from lying down. It happens because blood pools in the legs and feet and not enough gets back to the heart, lungs and brain. Low blood pressure can cause dizziness and lightheadedness as well as feeling off balance, unsteady, woozy or like you'll pass out or fall. In some people, low blood pressure leads to fatigue or thinking changes. While exercise can help, it's important to stay safe while working out.

### Strategies

+ **Pre-exercise energy.** It's good to fuel your muscles. But large meals can worsen low blood pressure. Have a small snack one to two hours prior to exercise. Popular options include a fruit smoothie, banana, nut (e.g., almond, peanut, cashew) butter and/or chocolate milk. Try different foods and combinations to find what gives the most energy and doesn't weigh you down or impact how well medicine works.

+ **Better blood flow.** You can wear leg stockings, called compression stockings, that keep blood moving back to your heart. These come in various pressures and lengths, and your doctor can tell you which to try. If low blood pressure is significant, you may also want to consider an abdominal binder, a tight waist band, that works the same way.

+ **Slow and steady.** Let your body adjust to a new position. If you've been lying down, sit for a minute or so. Once you're sure you don't feel dizzy, stand slowly and stay still for a minute or two before walking. The longer you've been in one place, the slower you should move. Before changing positions, wiggle your arms and legs. This tells your heart and brain you're ready to move.

+ **Have a seat.** You can do many exercises seated or lying down. Try a recumbent bike, seated elliptical, rower, or chair yoga, boxing or weightlifting. You're less likely to fall or hurt yourself when closer to the ground.

+ **Don't hold your breath.** Remember to breathe, especially when lifting weights. Holding your breath while straining can trigger the rest-and-digest nervous system, which could lower blood pressure and lead to passing out.

## Sweating: "I sweat too much or not enough."

With exercise, body temperature naturally rises. Sweat is the body's way of cooling off. Some people with PD have trouble regulating body temperature, which causes too much or too little sweating. This happens when Parkinson's impacts the nerve and brain pathways that control temperature (the autonomic nervous system).

Too much sweat is not only uncomfortable, it also can cause dehydration, fainting or drop in body temperature, especially in cold weather. Too little sweat could cause overheating and fainting.

### Strategies

+ **Weather or not.**

  – Monitor the weather forecast and plan around temperature, sun, wind and other factors. If it's warm, work out in the morning or early evening, when it's typically cooler. Exercise in the shade, if possible, and take water and rest breaks. If it's cold, try for the warmest and sunniest times, usually around midday. Wear sunscreen, even if it's overcast, and sunglasses when brighter. If it's windy, exercise closer to buildings and wear wind-resistant clothing.

  – Stay indoors if the weather isn't ideal. Walk around the mall or take a class at the gym or community center. Build a back-up plan for this scenario.

- Give yourself time to adjust. If you're used to exercising inside, slowly transition outside. You may not be able to exercise as long or as intensely because of varying weather, terrain and other conditions. If you typically walk 30 minutes on the treadmill, try 15 or 20 outside and gradually increase.

+ **Dress the part.**

  - If you sweat a lot or work out in warm weather, wear loose, lightweight, moisture-wicking clothes. Lighter colors are less likely to soak up heat. Consider cooling garments, too, which hold ice packs.

  - In cold weather, wear layers. Try wool or "technical" fabrics, which wick away sweat to prevent over-cooling. Wear a wind- and water-resistant top layer, if needed, and cover your head, neck and ears. Add or remove layers during exercise to regulate temperature.

+ **Keep your cool.**

  - For excess sweating, cool yourself and your space with fans.

  - For too little sweat, use a small, handheld, battery-operated fan with a spray bottle to mist and cool, just like sweat does.

## Memory or thinking changes: "I can't remember what exercises to do or how to do them."

People with PD, even in the earliest years, may have subtle problems with memory, thinking or planning. These changes can make it harder to design and follow an exercise program. If this happens, care partners and loved ones can be an important source of exercise support.

### Strategies

+ **Team effort.** Work out with a friend, family member or neighbor. Go for a walk, take a class or do another activity together. Invite a loved one to join exercise sessions or physical or occupational therapy appointments so they can help complete exercise "homework" throughout the week.

+ **Keep it simple.** Focus on a consistent routine instead of a complex schedule or complicated movements. Write your weekly exercise schedule on a calendar for reference. Do one-step, not multi-step, movements: a squat or a lunge, not a squat with a lunge.

+ **Take notes.** Write down instructions and equipment needed for regular exercises. List these on a notecard taped to the wall, print them in a binder you can carry to the gym or keep them in the notes section of your smartphone.

+ **Live and in-person.** Live (vs. on-demand or recorded), instructor-led classes offer step-by-step directions and feedback as well as the chance to connect with others. You can join in-person or online. Some classes are solely for older adults or people with memory and thinking changes.

## Freezing: "I sometimes get stuck while moving."

Freezing, or freezing of gait, is when your feet feel stuck, and you can't move forward. This can cause unsteadiness and falls. Freezing can happen when Parkinson's medication wears off or just out of the blue. It's commonly brought on by walking in small, crowded or unfamiliar spaces, passing through doorways or turning around. Freezing may not fully go away with medication or surgery, but exercise can help.



*Ethan Henderson, diagnosed with early-onset Parkinson's in 2016, enjoys running and hiking in the mountains near his home in Arizona.*

### Strategies

+ **Befriend the freeze.** Don't "fight" a freezing spell. Stop. Take a deep breath. Try to relax. Do a mental practice run of your next movement — picture stepping over a threshold, for example — before attempting it again.

+ **Keep tricks up your sleeve.** There are many different "cues" that can help you move through freezing. Your physical or occupational therapist can teach you a few options and help you practice.

+ **Don't follow the crowd.** Avoiding big groups of people or small spaces isn't, of course, always possible. But try to plan workouts for times and places with fewer people and more room. At the gym, for example, aim for late morning or early afternoon, when it's typically less busy and classes less full. Look for locations that are generally more spacious, such as parks or other outdoor areas.

+ **Walk to a different beat.** Practice walking (this can be your aerobic exercise!) to the beat of a metronome or specific music. This syncs brain and walking rhythm for a smoother gait and less freezing. A music and/or physical therapist can help you find music with the right beat or teach you to use a metronome app.

## Balance changes or falling: "I feel unsteady and I'm afraid I'll fall."

The older we get, the harder it may be to keep balance. That's why balance and strength exercises are so important as we age. People with Parkinson's, of any age, also may have trouble with balance, especially as disease progresses. Other symptoms of PD, such as slow, small movement, fatigue and even vision changes, also can impact balance. This makes it harder to catch yourself when caught off-balance, as with tripping, stumbling or stepping wrong off a curb.

If you have new or worsening walking or balance changes or falls, it's critical to see a physical and/or occupational therapist. These experts can help challenge and improve balance, prevent falls or limit injury with falls. They also can evaluate whether a cane, walker or other support may be helpful; match you with the right device; and teach you to use it during everyday activities and exercise.

## Cues to Move through Freezing

### Internal Cues

- **Positive attitude:** Reconnect with the here and now. Tell yourself you won't be stuck forever. Picture best-case scenarios, such as no freezing or quickly overcoming it. Limit worry and stress, where possible, as these can trigger freezing.
- **Mental rehearsal:** Pause. Review and visualize the actions to take a step — lift leg, lift foot, swing forward, etc. Then do it.
- **Internal dialogue:** Repeat "big steps" in your mind.
- **Visualization:** Imagine an object, such as a log or line on the floor, as a target to step over.
- **Gentle movement:** Rock back and forth or shift your weight side to side to build momentum.

### External Cues

**VISUAL**

- **Floor markers:** Focus on a change in floor pattern you can cross with your next step.
- **Cue cards:** Break movement into a series of steps. Write these on a card and post where you typically freeze.
- **Lasers:** Project a horizontal line, as a target to step over, via a device attached to a shoe, cane or walker.

**AUDITORY**

- **Verbal commands:** Recite "1, 2, 3, go" out loud.
- **Music and rhythm:** Hum a tune and step or march to the beat.

**TACTILE**

- **Touch cues:** A tap on the shoulder from a loved one, for example, can break freezing.

### An example of a "sit to stand" cue card

1. Move bottom to front of seat.
2. Place feet on the floor, close to the chair and slightly apart.
3. Put hands in position ready to push down on armrests or side of chair.
4. Lean forward with your nose over toes.
5. Push down through your legs and arms.
6. Count "1, 2, 3 and UP."

## Exercise Can Improve Balance and Lessen Falls

Sparrow, et al., *Journal of Neurologic Physical Therapy*, 2016

In this study, people with PD were randomly assigned to three months of active balance exercises or usual care. The balance program consisted of a progressive, highly challenging group exercise program for 90 minutes twice weekly. The program was effective in reducing falls, improving balance and reducing fear of falling.

### Strategies

+ **Pull up a chair.** You can perform many exercises, including stretching, strengthening and some aerobic activity, while seated. Using a stationary bike, for example, is a great way to safely exercise at high intensity. Many yoga studios and online programs offer classes you can do while sitting in a chair or while standing and holding onto a chair.

+ **Take a hike.** Or rather, use hiking-like poles when walking. Pole walking, also called Nordic Walking or Urban Poling, is using specially designed poles while walking. This engages your upper body and helps you stand taller, feel steadier and walk faster with larger steps.

+ **Dive in.** Water aerobics and other pool exercise can strengthen and challenge without the risk of falling. These activities are also low impact, so they're good for people with knee or back conditions or pain. Pay attention to water temperature as some feel colder temps temporarily worsen stiffness and other PD symptoms.

+ **One thing at a time.** Focus only on the task at hand. If you are walking, just walk. Don't hold a conversation, listen to music or carry anything. Doing two things at once can push you off balance more easily.

## Extra movement (dyskinesia): "Involuntary movement impacts my exercise."

Dyskinesia is involuntary movement that can happen after many years with Parkinson's and taking medications like levodopa. The movement can be writhing, twisting, twitching, jerking or fidgeting. Dyskinesia typically happens when medication is otherwise working well (during "on" time). For some,

## Katrina Long, occupational therapist and guide co-author, shares tips.



### Seated exercises

Sit in a stable chair, with a back and without wheels. While sitting, with your arms supporting you on the chair seat, do leg lifts for aerobic exercise. Alternate lifting each leg with the knee bent. For strength exercise, attach bean bags or light weights to your ankles. Also practice straightening your leg in front of you. Straighten your knee as far as possible, hold and relax. Repeat on the other leg. This builds leg strength and knee flexibility.



### Standing exercises

Stand behind a stable chair and hold the back with one hand for balance. For aerobic exercise, march in place, alternating legs. Lift your knee as high as possible, as if trying to reach your chest. Keep your back straight and don't crunch forward. Alternate which hand you use to hold the chair for balance.

it's barely noticeable. For others, it's bothersome. When significant, dyskinesia can impact everyday activity, walking or balance and even cause weight loss or fatigue. And all of these symptoms can, of course, affect ability to exercise.

### Strategies

+ **Budget wisely.** Each of us has a certain amount of energy to give. Dyskinesia takes some of that. If you think of energy like money, imagine you have one dollar to spend per day. Dyskinesia takes 20 cents, so you've got 80 left. How can you spend that wisely? Give activities a cost, like five cents for standing from sitting, 10 for going up and down stairs, a quarter for walking around the block. Rest breaks earn money back. Avoid overspending, which means you'll be in a deficit the next day and not able to do as much.

+ **Pace yourself.** Try "exercise snacks" — short periods of movement every few hours. This spreads activity and energy use throughout the day, so you don't use too much at once. If dyskinesia comes on, you can skip a snack or two where needed.

## Cramping (dystonia): "My muscles spasm when I exercise."

Dystonia is muscle cramping, spasm or tightening that pulls the fingers, toes or other body part into an awkward, sometimes painful position. Examples include your head turning sideways, foot twisting inward or toes



"I'm in late-stage multiple system atrophy, and I'm bedbound most of the time. So for me, there's a fine line between exercising and keeping moving. I'm at a point where it's okay to do other things, to just keep my limbs moving. Exercise was making my fatigue and other symptoms worse. But I still try to move — the commode isn't right next to the bed so I have to get up and over to it. And I do stretching in bed."

Hadley Ferguson

gripping the floor. Dystonia can happen when medication wears off, early in the morning or even with exercise. Because it can be painful and impact walking and other movement, dystonia can interfere with exercise.

### Strategies

+ **Opposites attract.** Stretch the muscles that cramp and strengthen the ones that work opposite. With biceps dystonia, for example, you'd want to stretch the biceps and build up the triceps. A physical or occupational therapist can show which muscles to target and suggest massage and other non-medication treatments, where useful.




*Jimmy Choi, diagnosed in 2003 with early-onset PD, makes exercise a regular part of a full and inspiring life with Parkinson's.*

+ **Take a different tack.** New approaches to the same activities might ease symptoms. Some runners with dystonia, for example, run backward (with a partner!) or change gait, switching from mid-foot to heel strike to avoid putting pressure on the toes. Try a couple of shorter exercise sessions instead of one longer, continuous session, to prevent or lessen dystonia.

+ **Build a time buffer.** For a 30-minute workout, plan an hour. If symptoms interrupt, you can take time to slow down, or stretch, massage or walk off the cramp.

"When we concentrate hard enough, we can lessen the effects of dyskinesia. But that takes so much concentration we usually can't do much else. So I concentrate on a simple exercise — like isometric holds. This is when you contract a muscle for a longer period of time instead of doing short, fast reps. I'll hold a squat for a few seconds rather than doing a quicker set of 10. Or I'll do a hollow hold (like holding a sit-up at the top) instead of multiple sit-ups. Agility training is good, too, because you have to concentrate on speed and direction at the same time."

Jimmy Choi




*Exercise is the best medicine for managing life with Parkinson's, according to Lynn Hagerbrant, with trainer Ansumana Touray.*



# Who and What Can Help?

The right people and tools can help you stick with exercise through the ups, downs and in-betweens of Parkinson's. Pick as many or few as are useful, and adjust, as needed, over time. The best supports are likely to change as Parkinson's, goals and exercise abilities change.

## Build an Exercise Team

Just as you've enlisted a group of people to support your Parkinson's journey, you can engage a team to support your exercise journey. (If you haven't built your PD team yet, don't wait!) Think of yourself as an athlete — who do you want in your corner? Better yet, what do you want or need to support exercise, and who can help? Is it motivation, a schedule, or exercises to stay injury-free? Could a loved one offer regular encouragement, a fellow exerciser help you stay on track and a physical therapist keep you moving as much as possible?



"I worked with an occupational therapist to relearn how to walk side by side with my wife, holding her hand and having a conversation without stumbling or losing balance."

Larry Gifford

By starting with what you need, you can create a team to meet those needs. If you're not sure what you need or where to start, your Parkinson's doctor and physical or occupational therapist can help.

## Do I have to do physical therapy, occupational therapy and exercise?

Not necessarily. But there are times in Parkinson's when PT and OT, even for a short time, may be particularly helpful. These include:

+ **At diagnosis**
  Even if you're a regular exerciser or have mild symptoms, try to see PT and/or OT soon after diagnosis. They'll test your movement, measure motor and non-motor symptoms that might impact activity and assess your physical activity and exercise levels. This is your "starting point," or baseline. From there, they'll design a personal exercise program that aims to lessen or prevent symptoms. This is called "prehab" — using therapy early, before symptoms like falls happen, rather than after they come on or cause injury, which is "rehab." Following initial sessions, check in with PT and OT every six to 12 months, at least. This lets your therapist reevaluate your symptoms, catch changes early, and adjust exercise or therapy for the most benefit.

## Who Can Help with What?

| Provider | How they support exercise |
|---|---|
| **Primary care and/or Parkinson's doctor** | + Give the "go ahead" to start or increase exercise, especially if you have conditions that affect heart, lungs or body, like diabetes<br>+ Optimize medication and other treatments so you can exercise to your fullest<br>+ Help structure your exercise team, recommending which professionals to include when |
| **Physical therapist (PT)** | + Offer exercises, tricks and tools to ease symptoms like imbalance, falls and freezing, which can impact exercise<br>+ Design and modify goal-directed workout programs from diagnosis throughout life with disease<br>+ Suggest local exercise classes<br>+ Recommend a cane or walker, when necessary, and teach to use |
| **Occupational therapist (OT)** | + Keep engaged in activities ("occupations") you care about<br>+ Assist in developing personal goals and reviewing progress and achievements<br>+ Help build and maintain healthy habits to improve quality of life<br>+ Support independence, considering your strengths, environment and activities that are important to you |
| **Music therapist** | + Use music and rhythm to improve walking, lessen symptoms like freezing and boost motivation<br>+ Work with PT and OT to design the best program for you |
| **Fitness professional** | + Serve as coach, cheerleader or certified personal trainer<br>+ Lead or instruct classes or help you carry out an exercise program<br>+ Teach to use gym equipment and practice proper form, and keep exercise fun and interesting<br>+ Collaborate with PTs and OTs who have Parkinson's expertise |
| **Mental health care provider** | + Talk through and treat mood changes, negative thoughts or behaviors that can interfere with motivation or ability to exercise |

+ **If you have balance problems or falls, especially if new or worsening**
  Therapists offer balance and gait training to help reduce falls and improve walking, both in and outside the home. They also provide postural training, which includes strengthening and stretching to counteract PD's effects on posture, such as stooping or leaning forward.

+ **If you have trouble with everyday activities**
  OT specializes in exercises and tools to help you move through daily life — getting dressed, typing or texting, driving, etc. — more safely and easily.

+ **If you have trouble starting or sticking with exercise for any reason**
  Therapists are uniquely trained to deliver exercise treatment in a way that works for you and meets your goals. Some people like to see PT or OT every few weeks or months to stay on track. Others like to go it alone and return for a "refresher" if they fall out of the exercise habit or new symptoms come on.



"I realized after watching Denise go to her classes that maybe I could join in, too. And I realized I felt better and benefited greatly once I did!"

Bernard Coley, husband and care partner of Denise Coley

## Make the most of your exercise team

As with all Parkinson's team members, it's important to develop a trusting and long-term relationship with your PT and OT. You need a partner who listens, understands and challenges you to bring out your best. Consider these tips:

+ **Get direction from your doctor.**
  Your doctor can guide you to the right providers for your symptoms and needs. They can make referrals and recommendations to specific providers. (You may not need a referral to start seeing a PT or OT.) You can also ask others in the PD community for input.

+ **Look for a Parkinson's expert.**
  See someone with experience in Parkinson's. If that's not available, see someone who works with people who have neurological conditions or are older. For PT and OT, check for certification in Lee Silverman Voice Treatment (LSVT) BIG, an intensive therapy designed for PD. Look for a PT who is a "neurologic clinical specialist" (NCS), which means they've completed rigorous training and testing in PD. Look for an OT who regularly treats people with Parkinson's and/or has completed PD education and certification. If you want to work with a personal trainer or other exercise professional, ask if they've undertaken Parkinson's training programs, such as a Parkinson Wellness Recovery PWR! Moves workshop. (See page 64.)

+ **Check insurance coverage.**
  While physical and occupational therapy visits may be covered, at least in part, the number of sessions allowed may vary. Contact your insurer (or ask the therapist's office to) to determine what you'll pay. If your coverage seems limited or variable, ask

questions — why it's changing, whether your doctor or therapist can advocate for broader or continued coverage, if different coding for insurance is needed on their end, etc.

+ **Do a trial run.**
Before you make an appointment, chat briefly with a potential provider over the phone, if possible. Ask about their background, education and experience. And ask about their approach — how they work with patients, measure results, etc. If it seems like a fit, try a session or two. But if it doesn't seem to be working, don't feel stuck. You can and should make a change. Many people need to see more than one person before they find their match. And some just want a fresh perspective after a bit of time.

+ **Start and end with goals.**
Your therapist should ask what you want to get out of treatment and help you set goals. Goals give meaning and purpose to your hard work. They also help your therapist design and carry out your personal program. And they give you a target, so you know when you're on track or where you need to work to get back on track.

+ **Be an active partner in your care.**
Be curious. Ask lots of questions. *What is this exercise meant to do? Why do we do it this way? Is it normal to feel tired, sore, etc.?* Make sure they explain until you understand. The more you learn, the more engaged and proactive you'll be.

## Track Your Progress

Keep an activity log. This shows progress toward goals and helps determine what's too easy or too hard. It's also a place to record what you're learning — about exercise, life or yourself, how you feel before and after exercise, when you seem to exercise best, and even which foods make a difference.

Mark the date and time; activity type, length and intensity; how you felt; and other relevant information, like whether you had pain, how you slept the night before, when you ate or took medication relative to when you worked out and any other useful details.



## Start Exercise Early in Disease

Ellis, et al., *Seminars in Neurology*, 2021

This paper highlights the growing body of evidence revealing the benefits of physical therapy and exercise to mitigate motor and non-motor symptoms, improve physical function and reduce disability in people with PD. The authors highlight the importance of starting exercise and physical therapy early in the disease course.

## Tools to Monitor Activity

| Tracker | Pros | Cons |
|---|---|---|
| **Calendar** | + Simple<br>+ Low cost<br>+ Low maintenance<br>+ At-a-glance view<br>+ Scheduling and tracking in same place | + Little room for detail<br>+ Easy to forget<br>+ May be less accurate |
| **Diary** | + Simple<br>+ Low cost<br>+ What and how much to record up to you | + Can be more to maintain<br>+ Easy to forget<br>+ May be less accurate |
| **Smartphone** | + Wide range of apps to suit needs<br>+ Likely always with you<br>+ Quick overview of daily activity<br>+ May provide motivation (to meet step or movement goal)<br>+ Incorporates goal setting<br>+ Includes GPS for route and distance tracking<br>+ May be more accurate | + Expensive if you don't already own phone<br>+ May involve a learning curve<br>+ Can be distracting<br>+ Could require internet access to process data<br>+ Tracking can shorten battery life |
| **Wrist device or smartwatch** | + Many types and styles to suit needs, preferences and budget<br>+ Low effort<br>+ Provides instant feedback and motivation to meet goals<br>+ May include step tracker, heart rate monitor and move reminders<br>+ Most accurate | + Can be expensive<br>+ Involves a learning curve<br>+ Can be distracting<br>+ Requires charging and syncing to process data |

# How can I support my loved one's exercise?

Many want to encourage their loved one to exercise, without feeling like they're nagging. This may be especially tough if your loved one has trouble getting into or continuing exercise. Consider these tips:

+ **Identify the hold-up.** Figure out what's getting in the way. Is it mood changes, fatigue, difficulty moving or something else? When you name the problems, you can brainstorm solutions together. But go about it gently. Before jumping to: *You need to exercise more!*, share your observations: *I've noticed you aren't going to boxing class as much. Has something changed?* Starting from a place of curiosity and care will, hopefully, open an honest discussion.

+ **Check in with yourself.** Ask yourself why you're adamant about exercise: Because the doctor said so? You see Parkinson's changing? You worry what might happen without exercise? You've seen the benefits firsthand? Examining your motivation can help guide your words and actions for the best effect.

+ **Bring in the experts.** Physical or occupational therapy can help a person get into, or back into, exercise. Weekly visits with "homework" provide structure. And they position the therapist as the exercise director, both in and out of sessions. *Your therapist (not me!) said you have to exercise twice a week if you want to help your balance.* Join visits too, where possible, so you can reinforce tips.

+ **Set a shared goal.** Think about something you both want to achieve and work toward it together. You might take a yoga class and then have a dinner date once a week; each train for a 5K walk, keeping the other posted on progress; or ride bikes in the park before making brunch on the weekend.

+ **Be a good role model.** Keep up your own exercise routine and invite your loved one to join. Your movement can motivate. And it helps you care for yourself, which is critical when caring for someone else.

+ **Learn from others.** Many families and care partners face similar challenges. Connecting with others gives a chance to share experiences, learnings and tips. (Check out MJFF's online Parkinson's Buddy Network. See page 64.) One spouse, for example, took the title of "Chief Optimism Officer" on his wife's Parkinson's care team. Maybe you're the "Encouragement Director" or something like that. This signals good intentions and brings a little lightness. Nagging isn't in my title, but encouraging is! *How can I encourage you to exercise?*




# What Does Research Say?

Science has made incredible strides forward in understanding exercise, and repeatedly proven the benefits of exercise for Parkinson's. Studies show that all types of exercise — treadmill training, walking, balance exercises, dance, tai chi, you name it — are beneficial. Thanks to research, exercise is now one of doctors' first and strongest recommendations for life with Parkinson's. And it's a tool that empowers people to take action to positively influence their journey.

But exercise is, simply put, hard to study. It's tough to strictly monitor and measure activity over long periods. It's even tougher to separate the benefits of exercise from the benefits of other healthy habits that often go hand-in-hand, like eating a good diet and keeping social connections. And it's hard to target exercise to one symptom or to one stage of disease. So, researchers do their best. That can mean smaller, shorter studies. Or studies focused on specific groups, like those recently diagnosed and not yet taking medication, as this gives the best chance to see if and how exercise impacts progression. It can also mean research results are hard to translate into everyday life — how do you "dose" exercise and stay on track without the supervision, accountability and encouragement a research study provides?

Still, researchers continue to push toward the ultimate goal — a unique exercise prescription for every individual. Just like a medication prescription, an exercise prescription would spell out exactly what activity to do, when, for how long and how often, based on one's symptoms, medications or surgeries, exercise preferences and challenges, length of disease, other medical conditions, schedule, finances, life situation and more. This is true "precision" or "personalized" medicine and it's the future of Parkinson's care.



**Keep an eye out for research highlights throughout this publication.**



*Bill Bucklew, center, with friends, finds inspiration for life with PD in the mountains.*

# Where Do I Go from Here?

There is tremendous value in moving more and engaging in exercise. And the more meaningful your movement is to you and your goals, the more likely you are to stick with it. The first step is to start — literally take a step! You aren't going to go from A to Z overnight. And that's okay. In fact, that's how it should be. Small steps make for sustainable progress. Aim for progress, not perfection. Something is always better than nothing. And it's never too late — you're never too far along in life or in Parkinson's to make a positive change. What can you do today?

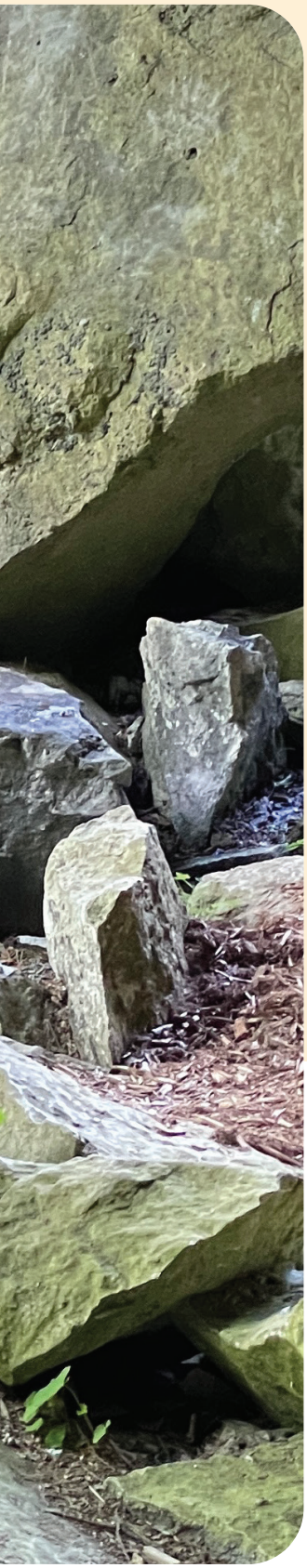


"Exercise is medicine. Because of the way I exercise, I was able to decrease how many levodopa pills I needed each day for the last few years. If you put in the effort, exercise becomes part of your Parkinson's treatment. Exercise is movement. And movement is medicine."

Richard Huckabee



*Dr. Soania Mathur, enjoying the peace of a day in nature.*



# FAQs

## Is something better than nothing?

Absolutely! As little as 10 minutes can make a difference. Maybe that's all you can do each day. Or, maybe it's best to break a 30-minute cardio session into three 10-minute bursts spread throughout the day.

## Is there such a thing as too much exercise?

In general, the more exercise you do, the better — to a certain point. Your body needs time to rest and repair between workouts, especially strength training. Be sure to give yourself time to recover and soak up the benefits. Over-exercising can lead to fatigue, injury, decreased motivation and more. Most importantly, listen to your body, monitor your symptoms during and after exercise, and modify as needed.

## I hear so much about certain exercises. What are:

+ **Forced cycling**
  Using either a tandem road bike, where two people ride together and the person ahead forces a quicker pedal speed for the person behind, or a stationary bike programmed to intermittently quicken pedal speed. Both approaches "force" people to pedal faster than they otherwise might. People with advancing Parkinson's may benefit the most from this type of exercise, particularly on a stationary bike. And there are various cycling programs, with and without the "forced" component, for people with PD.

+ **High intensity interval training (HIIT)**
  Short bursts of high intensity activity, at least 80 percent of maximum heart rate (see page 20), followed immediately by short periods of low- or moderate-intensity exercise. The ratio of high to lower intensity can range from 1:1 (one minute high, one minute lower), 1:2 or even 1:4 depending on your goals and fitness level. And the total workout could be less than 15 or more than 30 minutes. HIIT workouts are a great way to get a lot of high-intensity work in a short time and have been shown to have similar benefits to longer periods of moderate-intensity aerobic exercise.

+ **Boxing**
  Punching a weighted bag while moving your feet and stretching; works strength, coordination and aerobic fitness. Often involves shouting or grunting, too, which exercises the voice. And when done in a class, allows you to socialize and connect with others. There are programs specific for people with PD, such as Rock Steady Boxing.

+ **Golfing**
  The movements in golf, such as rotating your upper body while swinging the club and walking long distances between holes, can be beneficial. Golf may be more of a physical activity than exercise, depending on how rigorously you play. When done with a group, it also has a social component that's good for your body and brain. Weighted clubs and other tools designed for people with PD may be helpful for some.

+ **Dancing**
  Involves moving the entire body, typically to music. Can be done solo, with a partner, or even in a chair. Dance can improve motor symptoms and quality of life. There are many forms of dancing and programs for people with Parkinson's, such as Dance for PD.

+ **Swimming**
  A total body aerobic exercise that can be short or long distance, low or high intensity, and done in a pool or open water, like a lake. There are various types of swimming, such as breast or back stroke. Swimming allows your body to be supported by water, which lessens impact on your joints while allowing greater freedom of movement. Mind the water temperature as some say symptoms temporarily worsen in cold water. And note deep brain stimulation (DBS) has been reported to affect swimming ability in some, so proceed cautiously after surgery. Test your abilities in the shallow end of a pool and make sure you swim when feeling "on" and always with another person.

> "It's not 'no pain, no gain'; it's 'no pain, no pain.' If you feel pain with exercise, back off!"
>
> Richard Huckabee

## How hard should I push myself?

As hard as you can, which is different for everyone. It will depend on how much activity you're used to, your symptoms, other medical conditions and how you feel in general. Exercise should challenge but also energize you. As much as possible, aim for moderate- to high-intensity exercise.

Listen to your body to find the sweet spot — not too easy, not too hard. When exercising, you might feel tired or sore. But you shouldn't feel sudden, sharp pain; like you'll pass out; or like you can't catch your breath. After exercise, you could have mild muscle aching or fatigue, sometimes lasting a day or two. But that shouldn't limit how or how much you can move or how much energy you have for other activities. If it does, you may need to back off the intensity a bit.

## Do I have to exercise at high intensity?

It is true that the harder you can work, the more benefit you may get. But there's still much value in low-intensity exercise and even simple daily movement. Regular movement helps digestion, sleep, mood and much more. And it's likely that being consistent — keeping up regular activity for years and years — is just as or more important than the intensity of an individual exercise session.

## How can I make exercise more challenging or fun?

Over time, our bodies adapt. What was once nearly impossible may become too easy. One way to increase effort is to work out longer or harder. Trying new activities is another. Switch up your routine every few weeks or months. You'll work different muscles and keep yourself interested. Have fun with season-specific activities, like playing frisbee or volleyball in the summer

## Three-times-weekly Aerobic Exercise Is Ideal

Alberts & Rosenfeldt, *Journal of Parkinson's Disease*, 2020

Based on current evidence, the authors recommend that people living with PD engage in aerobic exercise three times per week for 30 to 40 minutes at a time. The goal exertion should be 60 to 80 percent of heart rate reserve, 70 to 85 percent of heart rate max, or 14 to 17 on a 20-point rating of perceived exertion (RPE) scale.

"Having goals motivates me. So I participate in different athletic races and competitions. This forces me to stay on track so I can rise to the challenge and compete at my best level, which gives me a great deal of satisfaction. That's what motivates **me** but what's important is finding what motivates **you**."

Parkinson's community member

and snowshoeing or ice skating (if balance allows) in the winter. Or try exercise that works your brain and body at the same time. Dance or doubles tennis force you to move in a physically demanding way while anticipating and responding to others' movement. And the social component allows you to exercise your brain and build positive relationships at the same time.

Turning exercise into a game, or "gamifying," is another option. You can set a daily step goal on your smartwatch, participate in friendly exercise competitions, or try to trace shapes with your walking or running route. (This is called GPS art.) Or play an interactive video or virtual reality game, use an app that gives you points and rewards for exercising or join your kids or grandkids in their natural, fun movement. You can even put on music and dance (and sing!) freely.

## What if my symptoms get worse during exercise?

For some people, tremor or other symptoms might worsen during exercise. This is because stress — even good stress like exercise — temporarily increases PD symptoms. It's not a sign of damage, harm or faster disease progression. But increased symptoms could interfere with exercise. Lifting weights, working on balance, or doing push-ups might feel less safe when you're shaky, for example. Modify activity when needed (swap the push-ups for planks), time exercise to when your medication typically works best and talk with your doctor about other options. These might include taking a little more medication before or during exercise, for example, to ease symptoms and keep you going. (More recently approved "rescue" medications that are designed to work quickly might be worth discussing.)

## What are the potential risks of exercise?

Like any treatment, exercise has possible benefits and risks. For most, the benefits far outweigh the risks. But risks could include injury, pain or falls. Limit your risk by talking with your doctor and exercise professional before starting or increasing activity, especially if you have heart, lung or other medical conditions. And be extra careful if you have symptoms like low blood pressure, fatigue, imbalance or involuntary movement (dyskinesia) that could cause unsteadiness or falls. You may, for example, want to avoid using the treadmill on your own if you have balance problems. Or you may want to do mainly seated exercises if you have low blood pressure. Everyone should avoid multiple days in a row of the same exercise, especially strength or weight workouts, as this can increase risk of muscle, tendon or joint injuries.

## Can exercise really improve balance and walking?

Yes! There is a large body of evidence that exercise — namely physical therapy focused on balance and gait training — can improve these symptoms, particularly for people in early to mid stages of PD. Improvement requires a certain intensity and duration, so it's best to consult with a physical therapist.

## Is there a point when I should stop exercising?

Exercise remains beneficial throughout Parkinson's. But as you and PD change, your exercise program and goals must evolve, too. With a little creativity and adjustment, there are ways to continue doing the things you love.

If you love biking but develop balance problems, for example, a four-wheeled, hand, recumbent or stationary bike might be better than a two-wheeled one. If you have pain or joint problems, you may need to back off, take a break or switch activities — less running, more swimming, for example.

If you wonder if you should stop exercising, talk to a physical or occupational therapist. They can help modify your routine and connect you with the right equipment and resources.



### Fun Exercise May Be Easier to Maintain

Van der Kolk, et al., *The Lancet Neurology*, 2018

In this study, people with PD were randomly assigned to either aerobic exercise done on a stationary bike at home or stretching. The aerobic exercise was enhanced with virtual reality software and real-life videos. (This is known as "exergaming.") The study provided preliminary evidence that aerobic exercise lessens motor symptoms and improves heart and lung (cardiovascular) fitness. There was also good compliance with the exercise program, which is important for sustained benefits.

## Does surgery or medication affect exercise?

Deep brain stimulation (DBS) or focused ultrasound (FUS) surgery, or medications that include stomach tubes, infusion devices or pumps may impact which activities you can safely or comfortably do. Always talk with your PD doctor and surgeon, who will advise when to restart or how to adjust exercise after a procedure or medication change.

After DBS, doctors generally suggest avoiding aerobic exercise or stretching of the arms or chest muscles, such as when swinging a golf club or tennis racquet, doing yoga or lifting weights, for four to six weeks. As you gradually resume normal activity, steer clear of activities with sudden, repeated or vigorous bending, twisting or stretching. A few people have had trouble swimming after DBS, so test your ability in the shallow end of a pool and swim with someone else, only when you feel fully "on." Because focused ultrasound does not involve a device, there may not be significant restrictions after the initial recovery.

Those with medication infusion pumps (such as for levodopa/carbidopa gel) should disconnect the pump before water activities and carefully clean the tube and skin after. Ask your doctor how to dose medication before disconnecting so you have enough for your workout.

When starting or changing any medication, for Parkinson's or otherwise, be cautious in the days and weeks following. Watch closely for side effects, such as lightheadedness, dizziness, shortness of breath or fatigue, that can impact exercise.



"Play! I've done exercise where I'm down on all fours, loudly urging on a voice-activated stuffed animal, racing another person doing the same. I'm working my body and voice, socializing and having fun!"

Larry Gifford

## Does exercise "use up" medication?

There's no evidence that exercise increases your medication needs. Instead, it may actually improve how well and how long your medication works. With exercise, brain chemicals like dopamine (which decreases in Parkinson's) and serotonin are released into the bloodstream. This can temporarily improve motor symptoms and boost mood. Remember, medication helps you exercise and exercise helps your medication.



*Lawyer Jim McNasby makes an active healthy lifestyle part of his approach to living with PD.*



*Lynn Hagerbrant with her husband Eric.*



# Resources

# Resources

This resource list is intended to point you in the right direction and highlight available resources. It is not a comprehensive list and is not an endorsement of any specific organization, provider or program.

## Exercise Care Team Members

### Parkinson's doctor, or Movement Disorder Specialist

The International Parkinson and Movement Disorder Society:
**mds.movementdisorders.org/directory**

### Physical Therapist or Occupational Therapist

American Physical Therapy Association:
**aptaapps.apta.org/APTAPTDirectory/FindAPTDirectory.aspx**

Lee Silverman Voice Treatment (LSVT):
**lsvtglobal.com/LSVTFindClinicians**

PWR! Power Wellness Recovery:
**pwr4life.org/professional-directory**

OT Potential:
**otpotential.com/occupational-therapy-directory**

### Music Therapist

The American Music Therapy Association:
**netforum.avectra.com/eweb/DynamicPage.aspx?Site=amta2&WebCode=IndSearch**

## Community Connections

Parkinson's Buddy Network:
**parkinsonsbuddynetwork.michaeljfox.org**

Parkinson's Unity Walk:
**unitywalk.org**

Run, Walk and Cycle Series:
**michaeljfox.org/news/run-walk-cycle**

Team Fox Endurance Events:
**michaeljfox.org/team-fox-endurance**

## Parkinson's Exercise Programs

Dance for PD:
**danceforparkinsons.org**

Daily Dose PD:
**dailydosepd.com**

Delay the Disease:
**ohiohealth.com/services/neuroscience/our-programs/delay-the-disease**

In Motion:
**beinmotion.org**

Invigorate:
**invigoratept.com**

Mind and Mobility Chair Exercises:
**mindandmobility.com/blog/3-chair-exercises-for-parkinsons**

Movement Lab:
**pdmovementlab.com**

Parkinson's Wellness Recovery:
**pwr4life.org**

PD Active:
**pdactive.org**

Ping Pong Parkinson:
**pingpongparkinson.com**

Rock Steady Boxing:
**rocksteadyboxing.org**

stoPD (support and training to overcome Parkinson's Disease):
**stop-pd.org**

## Other Resources

Adaptive Adventures:
**adaptiveadventures.org**

Challenging Parkinson's Disease through Exercise:
**challengingparkinsonsdisease.com**

PD Avengers Exercise Hub:
**pdavengers.com/exercise**

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"I think about this as risk management. I balance exercising as much as I can with the fear of hurting myself. I don't know where the line is. As you get older, knowing which exercises to do and not do becomes harder. My knee has early osteoarthritis, so now I watch how much I run. And if I do too many chin-ups, I start to have tendon problems. So I'm constantly reevaluating."

Parkinson's community member

# Note

Information in this guide was accurate at the time of publication in January 2024. For the latest on exercise and Parkinson's, visit **michaeljfox.org**.

Portions of this guide were adapted from the *Engage PD* workbook, part of a physical activity coaching program sponsored by Teachers College, Columbia University in New York, New York and Cardiff University in Cardiff, Wales. For more information, see the **Engage PD website** and Shih et al. in the reference section.

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

## About The Michael J. Fox Foundation

As the world's largest nonprofit funder of Parkinson's research, The Michael J. Fox Foundation is dedicated to accelerating a cure for Parkinson's disease and improved therapies for those living with the condition today. The Foundation pursues its goals through an aggressively funded, highly targeted research program coupled with active global engagement of scientists, Parkinson's patients, business leaders, clinical trial participants, donors and volunteers. In addition to funding $1.5 billion in research to date, the Foundation has fundamentally altered the trajectory of progress toward a cure. Operating at the hub of worldwide Parkinson's research, the Foundation forges groundbreaking collaborations with industry leaders, academic scientists and government research funders; creates a robust open access data set and biosample library to speed scientific breakthroughs and treatment with its landmark clinical study, PPMI; increases the flow of participants into Parkinson's disease clinical trials with its online tool, Fox Trial Finder; promotes Parkinson's awareness through high-profile advocacy, events and outreach; and coordinates the grassroots involvement of thousands of Team Fox members around the world.

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