MORE MOTION

2016, ISSUE 2

Balance Beam!

After her diagnosis, Renée Le Verrier sought a service dog to help her walk. She didn't know how much he'd also enrich her life.

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SPEAK OUT! Volunteering may help you feel better



Let's Take Action!

djusting to a new normal after a diagnosis of Parkinson's disease (PD) can feel daunting. Things like walking your dog, gardening, and coloring with the kids may now take a bit more time and planning.

But people with PD and their loved ones do live rich, fulfilling lives amid these challenges by staying actively engaged in their care decisions. From keeping physically fit to seeking a dedicated PD doctor or movement disorder specialist, there are many steps within your control.

Just picking up *More than Motion*™ is an action step. The title shows we understand that you're facing more than physical hurdles such as hand tremors and gait problems. In making routine decisions, you may encounter PD issues beyond mobility. It is a tall order to figure out how to communicate better with your doctor, navigate the healthcare system, work in partnership with your caregiver and manage to feel good about small successes.

These pages contain solutions you may be able to use to help you maintain control:

One woman with PD chose to rely on a trained canine companion instead of using a cane to help her move through her daily routine on her own terms and with greater fulfillment. A mother of three turned her diagnosis into a teaching moment by bringing the kids into the PD conversation. Meanwhile, some people who've consulted a financial planner are finding ways to both manage their care costs and maintain their standard of living.

The fact is, people with PD, their loved ones and the broader PD community are increasingly discovering and sharing these solutions. We're in this with you. We're ready for action.

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Newsroom

Events + Community + Solutions + Resources



What Is the World Parkinson Congress?

A CRITICAL MEETING THAT CONNECTS YOU TO A GLOBAL COMMUNITY THAT SHARES YOUR CHALLENGES AND INTERESTS.

hink of how much encouragement and know-how you gain from exchanging stories with others who either have Parkinson's or care for someone who does. Now, picture the conversation on a global scale and you understand the value of attending—in person or virtually—this year's fourth World Parkinson Congress (WPC), being held September 20 to 23 in Portland, Ore.

The massive gathering occurs every three years, drawing together not just people living with PD, but also physicians, neuroscientists and other healthcare professionals who are focused on daily solutions and finding a cure. WPC's inclusive workshops, roundtables and lectures cover topics ranging from "Assessment and Treatment of Anxiety" to "Strategies to Optimize Daily Living" and "How Parkinson's Disease Affects Sexuality and Intimacy." To extend the discussions and advice to everyone in the PD community, the conference offers built-in ways for you to participate virtually, if you can't physically make the trip (see the sidebar). Learn more at wpc2016.org.



4 Ways to Take Part from Anywhere



Listen in. A series of World Parkinson Congress podcasts titled "Portland Countdown" is streaming talks now through September on wpc2016.org. New ones are posted the first Tuesday of each month.



Instagram it. Browse the WPC photo feed on the social networking site and share pictures with the tag #wpc2016.



"Like" it. Read the posts on this magazine's Facebook page and click "Like" to spread news from the event with friends. facebook.com/parkinsonsmorethanmotion



Do a virtual run/walk. Download the WPCsponsored Power Through Project app to sign up for regular exercise prompts that add up to a virtual journey from Montreal, site of the last WPC, to this year's site in Portland, Ore. PowerThroughProject.org

t is possible to help others, while occasionally needing help yourself. It is also possible that the act of volunteering may boost your mood. Just ask World Parkinson Coalition (WPC) ambassador Ryan Tripp, who speaks on behalf of the group and promotes its event, the World Parkinson Congress. After practically creating his role, Tripp became one of 12 inaugural global WPC ambassadors around the time of the WPC 2013 in Montreal; the positions were created to advance the WPC goal of inclusion and to cultivate more community leaders like Tripp. "My cup is usually half full, not half empty," he says.

Tripp didn't always feel confident that he could manage his PD symptoms and be able to volunteer. A lifelong athlete and passionate physical education teacher, he was diagnosed with PD at 47, forced to take disability leave from his job, and plunged into depression. After he received counseling through a local PD support group, he says that pursuhelped him cope. He regained pride and an appreciation for work that he had not felt since his diagnosis. "My role as a WPC ambassador is similar to my roles as a parent and a teacher. I strive to provide an inclusive educational environment and I encourage others' participation in events. My volunteering style is an extension of my lifestyle," Tripp says.

Like him, others diagnosed with PD are finding opportunities to talk about PD groups' agendas in schools, write letters to state representatives, and use social media to broadcast events or rally monetary donations for PD causes. Sometimes such tasks may take one to three hours a month. Most everywhere, commitments are increasingly individual, online and upliftingall reasons that make volunteering worthwhile for Tripp.

He plans to serve as an ambassador again this fall for the WPC 2016 in Portland, Ore. "It is my responsibility to be part of the solution," he says.

Give back on your terms

Volunteer virtually.

Donating your skills entirely online is an empowering trend. Find opportunities at skillsforchange.com.

Raise funds online too.

American Parkinson Disease Association (APDA) provides a template and hosting support to help you create a page to attract donors to its site. Visit apdaparkinson.org/ PersonalCampaign.

Share your experience.

Your personal story is valuable to others battling PD. The Parkinson's Disease Foundation (PDF) invites you to try blogging about yourself as a way to inspire others at pdf.org/ en/personal_stories.

FROM LEFT TO RIGHT: OFFSET; COURTESY ALLISON SMITH

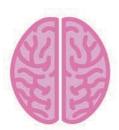
Good to Know...

The weekly number of hours of vigorous exercise that researchers associate with a slower progression of Parkinson's symptoms.



Young onset PD may progress more slowly, but its symptoms may be felt more intensely, according to the National Parkinson Foundation's Quality Improvement Initiative report.

Habitual exercisers appear less likely to develop Parkinson's, dementia and mild cognitive impairment, according to Mayo Clinic neurologist J. Eric Ahlskog, M.D., Ph.D.



In one study, exercise was found to prevent loss of brain cells, while being sedentary exacerbated cell loss, according to study author Florence Chang, a Mount Sinai movement disorders fellow.

ACTION STEPS

by Allison Smith



Consult your doctor to develop your fitness plan.



trainer or friend to stay on task.



progress far you've come will help



Fake it until Attitude is

PEER-TO-PEER





Allison Smith. MA, LMFT

Licensed therapist and personal trainer living with PD

Which exercise do you feel really helps you manage symptoms?

Walk! Walk to the mailbox, the park, take the stairs. Just do it regularly. Schedule walks (or any activity) as you would an actual appointment. I was 32 when I was diagnosed with young onset Parkinson's, and fitness (especially walking my dog) has always kept me mobile and improved my mood.

Find Allison's pro trainer tips and personal coping strategies on her blog parkinsonsinbalance.net.







SIMPLY OWNING A DOG IS LINKED TO BETTER HEALTH. FOR RENÉE LE VERRIER, DIAGNOSED WITH PD 11 YEARS AGO, THE IMPACT WAS MIRACULOUS.

et noses and thumping tails aren't the only reasons to love dogs. Researchers associate canine companionship with lower blood pressure, higher rates of exercise and an improved rate of recovery from heart attacks. There's even evidence that simply petting a dog helps chase away the blues.

If you think the challenges of Parkinson's disease mean that you can't enjoy these benefits, reconsider. We found that some dogs are being trained as not only companions, but also as helpers for people living with PD.

For Renée Le Verrier, a yoga instructor diagnosed with PD at age 43, getting one of these special service dogs (also called balance dogs) brought her much more than help to stand, walk and work independently. "He's part of my family," she says of Sir Thomas, a 140-pound, mantle Great Dane. "Tommy brings joy to my life."

Le Verrier applied for and met Tommy four years ago on a 12-acre farm in

Ipswich, Mass., that is home to Service Dog Project, Inc. (SDP). The nonprofit trains all of its gentle giants to assist people with movement disorders. SDP founder Carlene White, whose father also had Parkinson's, has raised more than 110 Great Danes to work as balance dogs for people with movement disorders such as cerebral palsy and multiple sclerosis, as well as PD.

With Tommy by her side, Le Verrier moves through her daily routine without the fear of being stuck or experiencing a fall. When her gait freezes, on command the Great Dane steps forward and gently tugs her along. "The most common thing he'll do is brace," she says. "He plants his paws, and when I shift my weight to his, it frees my foot to move. He also steadies my gait when my meds haven't kicked in yet," she adds. One unexpected perk is the reaction the pair get from passersby who focus warm attention on them rather than stare at Le Verrier's symptoms. "He gets noticed more than a cane and has much more personality."

Like all SDP pups, Tommy began training







when he was three weeks old to provide the special bracing support and prompting behavior that help Le Verrier. He can also help her step up from a parking lot onto the curb, assistance that is the difference between feeling stuck and getting on with her day. Thanks to the pet she nicknamed her "Great Dane Cane," Le Verrier-a busy wife, mom, artist and the author of several books on PD-has continued to work as a

"Tommy is part of my family. He brings joy to my life."

yoga instructor. Tommy even accompanies her to the yoga studio and waits patiently on his mat until her classes are over. (She likes to joke that he helps with the instruction by modeling the perfect downward-facing dog pose.) "I can be more independent, because he's there if I freeze or lose my balance," Le Verrier says.

Of course, there are days when roles are reversed, and Le Verrier becomes a typical dog owner taking Tommy to the vet or on an emergency nighttime walk because he ate something that upset his stomach. She finds the extra responsibility fulfilling, a fair trade-off for all that he does for her. "Just knowing he's around gives me confidence," she says. "I've been in my studio cleaning up after class and found my legs won't work. He gets me out of those situations. Whatever happens, we'll figure it out together."

IS A DOG FOR YOU?

Regardless of your physical limitations. a dog might help. Two considerations:



MOBILITY HELP

A GREAT FAMILY PET

THINGS TO ASK A...

Movement Disorder **Specialist**

Specially trained neurologists like Rebecca Gilbert, M.D., Ph.D., are the major-league head coaches of Parkinson's care teams: They've seen every possible PD symptom and can administer an array of treatments. "We're basically Parkinson's doctors," says Gilbert, a clinical associate professor of neurology at the Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at NYU Langone Medical Center. Here's what that means for you:

So specialists offer treatments that regular neurologists don't?

A | Yes. In the additional two years of training, we learn a lot about Parkinson's and specific procedures to help manage it. We give special injections for dystonia. an uncomfortable twisting or cramping of body parts; manage very complex drug combinations; and program deepbrain stimulation devices.

Since every PD case is different, how can you tailor the treatments so specifically?

A Unlike regular neurologists, we see a higher volume of PD cases. About 70 percent of patients in my practice have PD. So, even general neurologists who feel comfortable initially treating a PD patient will look to us for further expertise as symptoms become complicated.



Is that how most patients reach you? Referrals?

A | Yes, many come from neurologists who feel their patients need treatments they aren't comfortable giving. PD patients can have cardiovascular. urinary, gastrointestinal and psychiatric problems in addition to movement problems. Figuring out the treatment for a combination of motor and nonmotor symptoms, for example, can be tricky. But for Parkinson's doctors, that's something we do all the time.

☑ When do people benefit the most from seeing a specialist?

A | Some prefer to see us as soon as they're diagnosed. But we can help at any point. Upon diagnosis, we address how best to exercise, when to start medications, the best choice of medications, and which clinical trials you should consider. As non-motor issues emerge, we also help patients manage those.

Do you have a working knowledge of the newest therapies?

A | Yes. The Fresco Institute is a National Parkinson Foundation Center of Excellence, a designation that mandates that we conduct clinical research. We're experimenting with trans-cranial magnetic stimulation (TMS), a

> noninvasive alternative to brain surgery, and have on our radar "focused ultrasound," another potential treatment that is in clinical trials. What's coming down the pipeline is very exciting.

TIP

Find specialists through Centers of Excellence listed at parkinson.org.

STRATEGIES FOR HANDLING CARE CS STS

EXPERTS ON BUDGETING FOR CHRONIC ILLNESSES SHARE TIPS FOR MANAGING THE EXPENSES AND A FULL LIFE.

WRITTEN BY SARAH WATTS



diagnosis of Parkinson's disease will inevitably raise questions about the future. But how you'll manage to pay existing bills while also managing PD-related care costs doesn't have to be one of them.

In fact, there are quite a few resources that you or a loved one with PD can use to offset care costs and stretch your budget, once you talk with your doctor and family about how symptoms will likely progress.

Kathleen Campbell, president of Campbell Financial Partners LLC, has worked with retirees who have chronic conditions. Her advice to families of people who are newly diagnosed? Start having conversations with your children and partner as soon as you get the news. "Parkinson's is progressive, and nobody knows what the future will hold," says Campbell. "So let's start talking. If you're older, do you want to stay in your house? To what degree will you need assisted living, and who will be your caregiver?" she says, adding that addressing these questions now can take the stress out of decision-making and free you up to enjoy life.

The following are some strategies you may consider to help you plan:

Open an HSA

For couples with high-deductible health insurance plans, a Health Savings Account (HSA) may be a smart way to save on taxes. "An HSA allows you to accumulate funds and withdraw anytime you want for health purposes," says Ira Fateman, a certified financial planner and teacher at San Francisco

State University. "You don't have to pay taxes when the money comes out, if you're using the funds for health-related expenses, and you can use it for any qualified expenses, including long-term care, insurance premiums or assisted living." Furthermore, you can deduct the amount you contribute to an HSA on your tax return. A Health Savings Account must be linked to a qualifying, high-deductible plan. For your current plan to qualify, for instance, your deductible would have to be at least \$2,600 for family coverage or \$1,300 if the plan covers you alone. To check your eligibility and get help setting up an HSA, contact your employer's human resources department or a local bank.

Apply for SSDI Benefits

If clients can no longer work, Fateman advises them to apply for Social Security Disability Insurance, or SSDI. People who have paid into the Social Security system and qualify as disabled under Social Security guidelines are eligible.

Meanwhile, carefully consider when to take your regular Social Security retirement benefits. "The way the Social Security system is structured right now, you lose a substantial amount of benefits if you file before full retirement age, which is 66 for most people," Campbell says. Filing at 62, for example, will reduce your monthly benefits by about 30 percent.

One upside: According to the National Institutes of Health, the average age of diagnosis for Parkinson's is 60, with five to 10 percent of patients diagnosed before age 50. In other words, most Americans are still working when they're diagnosed.

"If you can keep working, that's a great thing in all regards," says Fateman. "Financially, it will give you time to prepare a budget and provide cash flow."

Tap Retirement Savings

For most, retirement vehicles like traditional and Roth IRAs get used to supplement retirement costs after the age of 591/2. But drawing on these funds can be helpful for Parkinson's-affected families as well.

"An IRA provides a minimum safety net if you're diagnosed," says Fateman. Once a client meets the IRS qualifications of disability, they can start to withdraw money from their traditional and Roth IRA accounts without penalty, regardless of age. Just be aware that you must still pay income tax on the amount withdrawn from a traditional IRA.

Consider a Reverse Mortgage

For couples who need extra income, reverse mortgages can be a "definite resource for people with Parkinson's." Fateman says. "Reverse mortgages can enable a client to stay in their home and solve a cash flow problem," by tapping the equity in the property.

Not everyone qualifies for a reverse mortgage, however. Applicants must be at least 62 years old and live in the home as a primary resident, according to the U.S. Department of Housing and Urban Development. Fateman recommends consulting a qualified reverse mortgage counselor to find out if you're eligible.

No matter what your circumstances are, communicating openly is the best way to make a plan.

Your Pocketful of Resources

SAVE THIS QUICK LIST OF WEBSITES AND SERVICES TO GET YOU STARTED.



FIND A PLANNER

The National Association of Personal Financial Advisors provides a directory of certified financial planners at napfa.org.



RESEARCH OPTIONS

Find information on Medicaid. reverse mortgages and more at aarp.org.



GET HELP PAYING FOR MEDS

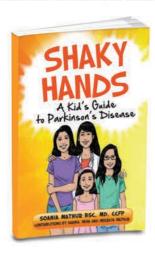
RxAssist is a site that provides links to patient assistance programs for help with prescription costs. Visit Rxassist.org.

Family Values Parkinson's disease wasn't part



oania Mathur, M.D., was 27, pregnant with her first child and working as a family physician when she learned that she had young onset Parkinson's disease. "All of a sudden a happy occasion was marred because of this diagnosis," says Mathur, explaining that the news rocked her expectations for motherhood. "I knew it was an incurable, progressive illness," she says.

At first she simply denied it, hiding her tremors from friends, colleagues and patients in her practice outside of Toronto. Avoidance was easy back then because her symptoms were sporadic and didn't warrant medication yet. She weathered her first pregnancy without



drugs. Her eldest daughter, Sarika, was born healthy and without complications. But then Mathur and her husband Arun had two more daughters, Neha and Meeraya, and each pregnancy was more difficult. "My symptoms got worse, and I couldn't take any medication because I didn't know what effect it might have on my unborn babies."

As the girls grew older, Mathur began to manage her symptoms with meds but still avoided the subject of PD. Having a strong, supportive husband helped her maintain a sense of normalcy at home: Although a surgeon with his own busy practice, Arun got up at night with the girls as babies, took them on playdates as toddlers, and later shuttled them between home and school, whenever Mathur's tremors were particularly bad. Meanwhile, the girls didn't ask why Mom's hand trembled sometimes and

caused her to color outside the lines or splash bright nail polish over the edges of their tiny fingertips. "I'm addicted to my girls. I always wanted to be involved in all aspects of their lives."

Then, Mathur's habit of waiting for meds to mask her symptoms before leaving the house started interfering with her ability to enjoy her children. Daily life was all about trying to juggle medications, symptoms and her daughters' needs. "We'd run late to social events or to school. It all became very logistical. Timing was everything," she says. "Because I hadn't come to terms with my diagnosis and only focused on what the disease was taking away, I was becoming someone who couldn't laugh as readily and wasn't enjoying life with my children."

After 10 years of hiding her diagnosis, Mathur decided it was time to own it, to take control of how she faced the challenges of PD. She decided to open up to the girls by providing them with basic facts about her condition-give it a name. One evening, after returning home from a fundraiser, the Mathurs asked their daughters if they knew why the family attended Parkinson's events. The couple saw it as a good time to ease into the PD conversation without scaring the girls. The reply they got from eight-year-old Neha surprised them: "Because you have Parkinson's," she said. Mathur's fear of burdening them with her diagnosis melted away. They already knew. What's more, they wanted to help, and decided that night to donate part of their allowances to Parkinson's research, so that their mom "wouldn't have to have Parkinson's anymore."

"It was an eye-opener. They intuitively knew, but we had never discussed it," Mathur says. "What I thought would be stressful, suddenly became a beautiful lesson."

A Lesson in Acceptance

In fact, being open with her children helped Mathur to be more honest with herself. She made a series of big decisions. First, she retired from practicing medicine to focus on volunteering with several PD organizations, including the

World Parkinson Coalition and the Brian Grant Foundation. Then, she began writing about living with Parkinson's for mainstream news websites. She has even published two children's books on PD. The second, Shaky Hands: A Kid's Guide to Parkinson's Disease, perhaps is the most special because her daughters helped her write it.

"As infuriating as this disease is at times, it has taught me to face each day with a sense of gratitude and optimism," says Mathur. What has her struggle taught her children? "That life will have challenges. But it is how you face them that's important."

Tips for **Talking to** Kids About PD

- Be honest. Hide the truth, and they may create a story that's much scarier. Besides, kids are intuitive and probably already know something's up.
- Express hope. Children are naturally positive and compassionate. This is an opportunity for them to express that. Help them to look for the silver lining.
- Keep the facts simple and easy to understand. Consider their ages and maturity before sharing too much. Mathur's first book, My Grandpa's Shaky Hands, is ideal if you have preschoolers.
- Let them help. Give them specific tasks, such as programming your phone with medical reminders, helping you with minor chores around the house, or getting involved in fundraising.

















8 things to remember

HERE ARE YOUR TAKEAWAY TIPS FROM THIS ISSUE OF MORE THAN MOTION".



- Connect with the PD community. Track news of the World Parkinson Congress by visiting wpc2016.org.
- Volunteer online. Opportunities to advocate from the comfort of home are listed on volunteermatch.org.
- Move more. Talk with your doctor about establishing a safe, fun exercise plan during your next visit.
- Get a pet. Owning any type of companion animal may help boost your morale. Browse for potential furry friends at aspca.org.

- Get help paying for meds. Caregivers, patients and doctors can research sources of prescription assistance at Rxassist.org.
- Talk about PD with the children in your life. Start with Soania Mathur's tips published in her books and on her website designingacure.com.
- Make an appointment with a movement disorder specialist. Search the National Parkinson **Foundation Centers** of Excellence at parkinson.org.
- Travel. Brief roadtrips may help you recharge. If that's not an option, escape with virtual reality apps that simulate excursions. Visit store.google.com.

Going Places

MARCUS CRANSTON, A GLOBE-TROTTING PHYSICIAN WITH PD, TOLD US HOW HE MAKES THE MOST OF TRAVEL.



Six years ago, while I was working as both a physician and a U.S. Air Force colonel, I was diagnosed with Parkinson's disease. At first, I worried that it might rob me of

my passion for traveling and outdoor activities. So, as a way to fight back, I launched a campaign to run four miles—in 44 countries! After a nine-month period of intensive planning, I'm proud to say that I completed my mission, while helping to raise global awareness of PD. Now that I'm retired from active duty, but still practice medicine, I have a bit more time to squeeze in trips. I'm up to 121 countries and counting. If that sounds like a tall order for you, take it from me: It doesn't have to be. Here are tips that helped me go from worrying before trips to happily wandering. I hope they'll help to make your journey more rewarding too.

Plan the cycle of your medications according to the time changes and time zones for your trip.

Pack crucial items in both your carry-on and your checked luggage. That creates a back-up kit in the event that you need to visit a clinic. If you have a neurostimulator in place, bring along documents explaining it, to ease your passage through security. Review all treatment and travel plans with your physician.

Schedule around your jet lag. Fatigue and sleep difficulties are a major part of Parkinson's. So, you might not want to schedule a tour on the day you arrive. Take time to rest and adjust.

Enjoy the trip-planning stage. Treat yourself to books and documentaries about your destination. Additionally, research Parkinson's support groups in the places you're headed. Reaching out to others can make travel much more enjoyable.

Stop worrying! Most difficulties of travel are overestimated. Just be as careful as you can, plan ahead, and you can go anywhere!



Click for Community

The Parkinson's More than Motion™ Facebook group is an active online community for breaking news, event listings and key resources about Parkinson's disease. You can ask questions, get answers and meet people just like you. Visit parkinsonsmorethanmotion.com.

4 REASONS

TO LOG IN AND JOIN US ON FACEBOOK



1. Great stories, photos and videos



2. Access to a vibrant community



3. A helpful guide to resources and events



4. A free subscription to MTM magazine

Join our online community at facebook.com/parkinsonsmorethanmotion





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