MORE MOTION



LET'S HELP EACH OTHER

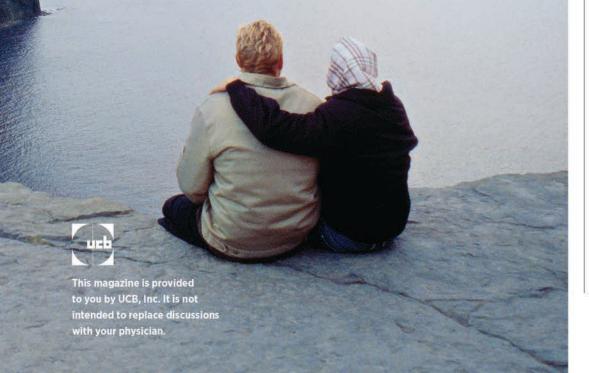
JOIN FORCES—whether you're living with Parkinson's or are a caregiver for someone with the disease, you don't have to go it alone. There are many ways to find a helping hand: you can seek support from doctors and researchers, private organizations, friends and family, and from those in your community who battle PD every day.

This magazine is also here to serve you. More than Motion™ is inspired by the fact that Parkinson's is more than what others may see: the tremors, gait problems and motor challenges. It's also felt in changes in appetite, sleep disturbances and emotional distress. And it's felt by friends and

family, especially caregivers.

In this issue, we want to help lessen the load by bringing the community to you. You'll find a host of lively bloggers and uplifting and educational social media suggestions, as well as a feature on how to strengthen the ties between caregivers and patients. We've also invited an architect and a dietitian to offer tips for living with PD, and we profile a doctor whose take on life after her diagnosis is truly inspirational.

Knowledge is power. We want you to learn as much as possible about PD so that you and your doctor can plan the best course of treatment for you. You don't have to go it alone.



EDITORIAL BOARD



Mike B. Aiken, S.C. Diagnosed 2002



Jo-Ann G.Rolling Meadows, III.
Diagnosed 1997



Mary Dee M. Redmond, Wash. Caregiver



Join Us.
Our Facebook
page loops you
in to our latest
news. Like us at
Facebook.com/
ParkinsonsMore
ThanMotion.



Inventions Lead the Way

Innovation gives us reason to be hopeful. These items—available now or in testing—can help make daily living with Parkinson's disease easier and more comfortable.

Stay Steady

Lift Labs, acquired by Google, designed **LIFTWARE** table utensils. The handles are embedded with technology that responds to the hand's tremors and then steadies the utensil, even when shaking. This kind of tech, which was supported by the National Institutes of Health, has so much potential that companies are looking at ways to use it for drinking and personal grooming. Order at google.com/liftware.

Button Up

For patients with motor skill problems, getting dressed can be stressful. **MAGNAREADY** sells cotton button-down shirts and casual shirts for men and women with buttons that close with magnets. Patients can dress themselves independently and quickly without worry. To order, visit magnaready.com.

Real-Time Research

The PARKINSON mPOWER APP (Mobile Parkinson Observatory for Worldwide, Evidence-based Research) is a brand-new iPhone app that allows PD patients (and those without PD, as controls) to track their symptoms in real time and share that data with researchers. The app uses questionnaires and data from activities such as finger tapping and walking, allowing users to participate in the biggest and most comprehensive study of Parkinson's disease. Learn more at parkinsonmpower.org.

Sensing Opportunity

A 9-year-old girl in Chicago was inspired to make a spill-proof, unbreakable cup after watching her grandfather cope with Parkinson's disease. With the help of her father, she designed the

she designed the KANGAROO CUP.

Its three legs give it a stable base that doesn't easily tip. The family launched a Kickstarter program and successfully raised funds to move forward. Order the \$13 Kangaroo Cup at Imagiroo.com.



\$70 billion

The amount the wearable electronics business is expected to reach in 2025, up from \$20 billion in 2015.





GOOD FUN Cartoonist Peter Dunlap-Shohl draws on humor to manage PD.

BLOGS TO FOLLOW

Sharing experiences about living with PD is a great way to find community and share resources. Here's a lively roundup.

- Off and On: The Alaska Parkinson's Rag With wit and flair, Peter Dunlap-Shohl writes and draws about the challenges of PD. Ranked a top blogger for those with the disease, the former Anchorage Daily News cartoonist has a graphic novel coming out about Parkinson's called My Degeneration. "There was nobody else I could find making comics about Parkinson's," he says, "so I thought it would be interesting and fruitful to try it." offandonakpdrag.blogspot.com
- Living Well With Parkinsons Disease Sheryl Jedlinski, who lives with PD, blogs about everything from cooking to family to physical therapy. She is also co-founder and editor of PDPlan4Life.com. livingwellwithparkinsonsdisease.com
- A Soft Voice In A Noisy World: A Guide To Dealing And Healing With Parkinson's Son's Disease Karl Robb chronicles the ups and downs of living with Parkinson's since age 23 on a blog that shares its name with his book. asoftvoice.com
- Studio Foxhoven Artist Terri Reinhart discovered a creative outlet with her blog.
 "I started writing when I was diagnosed with Parkinson's. It helps me to process all the crazy, wonderful things in life," she says. studiofoxhoven.com
- Life as Us Eric Neiman shares the ups and downs of young-onset Parkinson's disease, as well as the joys of raising a family with wife Alli—not to mention being in the funeral business. One post is about making their nursery PD-friendly. lifeasus.com
- Journal of Parkinson's Disease Award-winning journalist Jon Palfreman blogs about Parkinson's research at the online home of JPD, a resource for patients curious about where the field is headed. journalofparkinsonsdisease.com/JPD/Jon Palfremans Blog.html

SOCIAL MEDIA

Join the Parkinson's community on social media for real-time opportunities to engage, learn and find inspiration

INSTAGRAM

lifeaseric

Blogger Eric Neiman (left)

friendsofparkinsons

a nonprofit in Nevada

michaeljfoxorg

The Michael J. Fox Foundation

Hashtags categorize images and spotlight trends. Search:

#parkinsons

#parkinsonsdisease #parkinsonsawareness #parkinsonswalk

TWITTER

@asoftvoicepd

Karl Robb (left) Author and blogger

@dunlapshohl

Peter Dunlap-Shohl (left) Cartoonist and blogger

@MichaelJFoxOrg

Dedicated to finding a cure

@ParkinsonCafe

A hub for people with PD

@ParkinsonDotOrg

Research, education and outreach from National Parkinson Foundation

@ParkinsonRF

Parkinson Research Foundation sponsors research, funds education and more



Find More than Motion

on Facebook and join the 75,000 people who have liked our page to learn more about Parkinson's disease. Facebook.com/ ParkinsonsMore ThanMotion



Michael J. Fox Foundation

Fox Trial Finder helps match volunteers with clinical trials for the development of better Parkinson's disease treatments

ast-tracking better treatments—and ultimately a cure—for Parkinson's is the goal of
The Michael J. Fox Foundation's Fox Trial Finder tool, which connects scientists studying the disease with people willing to take part in that research.

"There's nothing that can move things forward faster than people coming through

the door to participate in clinical trials," says Claire Meunier, vice president of research engagement at The Michael J. Fox Foundation, "but finding volunteers is a challenge. About 80% of trials are delayed and 30% never get off the ground due to lack of volunteers."

Prospective volunteers can register with Fox Trial Finder at foxtrialfinder.org. They enter information such as age, ZIP code, symptoms and medications, and then receive an email once a week describing nearby trials that may be a match.

Clinical trial coordinators can also search the database to find the appropriate volunteers for their studies and then message them through the tool, which strips away all personal identifiers, such as name, phone number and email address.

Trials have a great need for volunteers. After all, says Meunier, all of today's treatments are available because people took part in past trials. "If you're frustrated because care hasn't improved faster, or you're eager to find a way to engage in the Parkinson's community, the Fox Trial Finder tool can help you connect," she says. "By participating, you'll make a significant contribution to the future and help get us to the finish line—a cure—much faster."

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Parkinson's trials recruiting

CLINICAL TRIAL PARTICIPATION

WHAT YOU NEED TO KNOW

Why Volunteer Scientists conducting trials of potential PD treatments need volunteers of all ages with Parkinson's. They also need family members of people with the condition—as well as people without any genetic connection to the disease at all.

Get Involved Not every trial is right for every person. A coordinator will walk you through the informed consent process, explaining everything you'll be asked to do, as well as all the possible benefits and risks.

How It Works There are trials that test new medications as well as studies that don't involve drugs at all. Some researchers are studying the effects of exercise, while others follow people over time to record their health changes.

Visit foxtrialfinder.org and register to find a clinical trial that might be a match for you.

TRIAL FINDER STATS

44,288 People registered

14%

Enrolled in a trial

Improve Your Living Space

The design of your home can make your life easier. Architect **Barbara Bouza** shares tips.

CREATING A SAFE, EASY HOME boosts quality of life when you're living with PD. Designers who specialize in crafting environments for people with health challenges can offer helpful tips. Barbara Bouza, managing director of Gensler design firm's Los Angeles office and leader of its Health & Wellness and Life Sciences Practice Areas, answers key questions.

Q: What are top considerations for the home?

A: Priorities should be around safety, open space, natural light and furniture placement to maximize accessibility and minimize hazards. Remove obstacles and clutter, and add alcoves and storage areas. Look for low-profile furniture and pieces with locking wheels so you can move and stabilize them easily.

Q: How can the right lighting help?

A: People with Parkinson's can have visual issues, so using both natural daylight and light fixtures can improve safety and mood. Locate light switches for easy access. Streamline window coverings and clear clutter to let in natural light. Consider circadian lighting, which uses a spectrum of light to mimic biological light-dark cycles. Solar tubes can lighten interiors like hallways, closets and bathrooms.

Q: What safety features can people add?

A: Reduce tripping hazards by leveling transition areas (from carpet to wood floors) with materials of similar height and dimensions. Secure area rugs with nonslip-backings. Vinyl, tile and low-pile carpet provide good traction. Manage cords and cables by bundling them (organizing stores offer options).

Q: What about design for the bathroom?

A: Look for space-saving fixtures. Consider possible challenges, such as the step into a tub. Showers with a low curb may be easier to handle, and some tubs have a door for easier access. Increase appeal of assistive fixtures like grab bars by picking complementary colors. Vinyl flooring can be installed with curved edges that flow up the wall a bit, eliminating those cracks that are hard to clean.

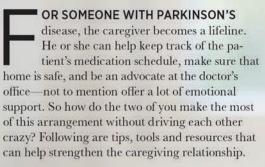
O: What about the kitchen?

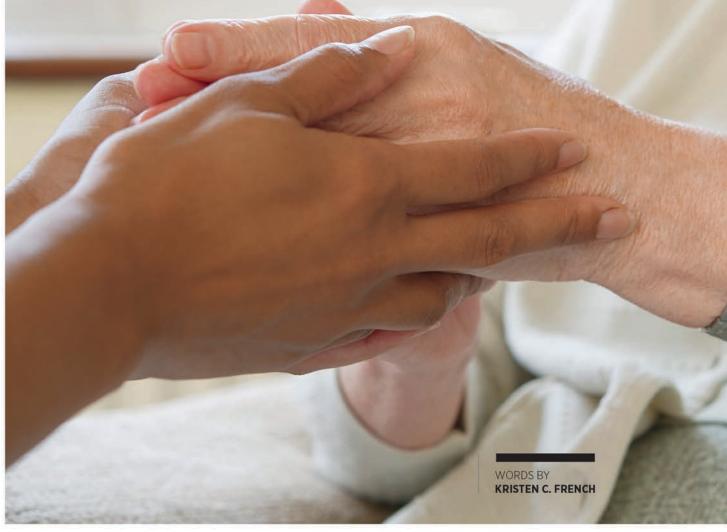
A: Create an island lower than standard counter height so you can sit to prep food. Pull-out organizers make it easier to reach needed items, and consider easy-tograsp cabinet door hardware.



NEW TOOLS FOR CAREGIVING

Improve your patient-caregiver relationship with organizational websites, informative wearables, useful apps and more





Get Organized

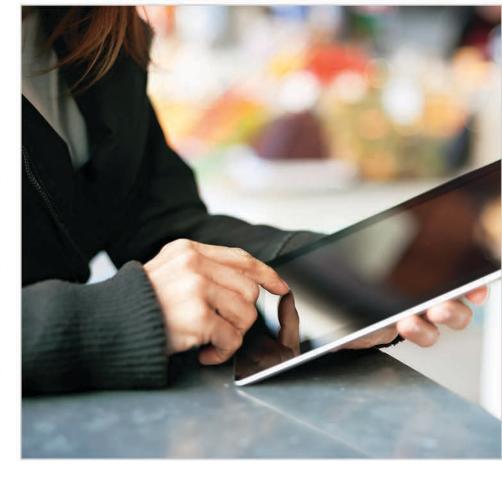
There is a lot to manage when it comes to PD, but websites and apps can help you stay on top of things. The National Parkinson Foundation has a helpful page on its website called "How Do I Get Organized?" Here you can find a series of key checklists that cover everything from advanced directives to contact information for the family vet. The National Parkinson Foundation also has an app, Parkinson's Central, which offers a host of useful features. You'll find a convenient "near me" tool for Parkinson's services in your area, tips on how to get the most out of doctor's visits, information on insurance and finance, and special caregiver content. The website CareZone and its app allow you to keep all of your family's health information in one place. You can get your contacts organized, keep a journal, store photos of important documents like a driver's license, and sync appointments and refill reminders with other calendars.

Find Great Care

A growing network of 41 Parkinson's Centers of Excellence around the world are staffed by the world's leading Parkinson's specialists. These centers are carefully selected by the National Parkinson Foundation based on 21 different criteria (a focus on comprehensive care, evidencebased treatment and cutting-edge research, for instance). If you aren't near a specialist, Johns Hopkins University currently offers the Global Telemedicine Clinic for Parkinson's Disease, a new initiative to provide one-time, web-based video consultations for people with PD. Due to state licensure rules, U.S. patients are eligible if they live in California, Delaware, Florida, Maryland or New York. If and when you're looking for an in-home assistant, CareLinx may provide ideas. The online community of professional caregivers provides caregiver profiles, background checks and screening. Or if it's time to consider a full-service home, try Caring.com, which offers state-by-state guides and reviews of the best senior care facilities.

Track Meds and Symptoms

You likely already have a pillbox, schedule and timer. But did you know that some pharmacies offer to organize the medications for you, and even send them to your address every month, often for free? For the technology-averse, the National Parkinson Foundation also has a



The new
Parkinson
mPower app
is part of a
study to collect
and track
symptoms of
PD progression
to better
understand the
disease, and
how wearables
can help
measure it.

customizable Excel spreadsheet. And the Day by Day Parkinson's Diary, a paper notebook, allows you to monitor food and medication times as well as record feelings throughout the day. If you prefer working off your smartphone or a tablet, there are some great apps that manage medication scheduling and allow you to record symptoms and share them with a doctor. Check out Medication Tracker, Parkinson's Disease @Point of Care, or PD Life, to name a few. Managing My Parkinson's also offers a digital journal and creates easy-to-understand charts that record test results and medication adherence.

Monitor Movement, Stay Safe

Monitoring movements of a PD patient can help them and caregivers see the bigger picture of physical challenges. Kinesia 360 is a continuous monitoring system that includes wearables and a mobile app. It comes with two sensors, one for the ankle and one for the wrist, and is aimed at measuring tremors, bradykinesia and dyskinesia. Other wearables such as AT&T's EverThere, Philips Lifeline or the Cuff line of

wearable jewelry can help track falls and location, and alert family members in an emergency via wireless signal. The Lively watch provides step counting, family alerts, medication reminders and a one-push help button.

PD patients can help give back to the community by contributing to research. The Parkinson mPower app (Mobile Parkinson Observatory for Worldwide, Evidenced-based Research) is a brand-new app that's part of a study to collect and track symptoms of PD progression to better understand the disease, and how wearables can help measure it. Through the use of surveys and tasks, like tapping buttons on your phone using two fingers, the app measures dexterity, balance, gait, voice and memory.

Speak Up About the Awkward Stuff

Some Parkinson's symptoms and side effects from medications may be difficult or unpleasant to talk about. But don't be shy about discussing them with the doctor. He or she may be able to adjust the dosage, or can suggest other therapies. Keep careful track of any symptoms or side effects you would like to discuss, and Don't be shy about discussing side effects of medication with your doctor. He or she may be able to adjust the dosage, or can suggest other therapies. send a list ahead of time if the doctor accepts digital records. A site such as PatientsLikeMe may be beneficial. It's best to talk to your doctor for medical advice, but at this online platform, individuals can connect with others who have similar conditions and share experiences.

Find Support

You're probably aware of the many support groups out there for people living with Parkinson's. The Parkinson's Disease Foundation, for example, offers a toll-free number for anyone looking for a support group in their area (that HelpLine is 1-800-457-6676). But there are also support groups for caregivers of all kinds, such as the Well Spouse Association or Family Caregiver Alliance. Check the websites of these groups to join online forums. Thanks to the Internet, you can also watch caregiving webinars, which address everything from mealtime and swallowing to the rise of new technologies that support caregivers. With websites such as Lotsa Helping Hands, you can keep family and friends in the loop, and get help for specific tasks or share caregiving responsibilities. After all, caregivers don't have to go it alone.

CARING FOR THE CAREGIVER

MARY DEE M. TOOK STEPS TO HELP HER HUSBAND-AND HERSELF

ary Dee M. recently had to make a difficult decision. She had been caring for Kurt, her 72-year-old husband of 47½ years who has PD, at home for almost a decade. But after her shoulder surgery, and after Kurt's many falls, she no longer felt strong enough to help him in case he fell. Even the emergency team, after several responses, suggested that she look at placement for him. "They saw that his needs were greater than I could answer to," she says.

Though Mary Dee and Kurt resisted at first, their family and friends, as well as Kurt's doctors, all encouraged them to find Kurt a placement outside the home where he could be adequately cared for. With professional help, Mary Dee found him an outstanding home with great amenities and safety features. Although she struggles with some guilt two years later, Mary Dee knows that he's safer, and it allows her to be more present when she sees him. She now takes a few days for herself so she can keep up with her own appointments and emotional health. Kurt occasionally returns home for a visit during the warmer months, but has many visitors and has made fast friends at the home.

This is a classic problem for caregivers: remembering to take care of themselves and to get outside help when they need it. Caregivers who try to do too much, or neglect their own health, can burn out and become much less capable of providing the



care their loved ones need. "My goal has always been to keep him safe and give him the best life possible," says Mary Dee. "When I saw that it was beginning to take a toll on me, and others saw that, and I aged physically, I thought, 'I have no choice but to make a decision to help us both."

WORDS BY BRIGID ELSKEN GALLOWAY PHOTOGRAPHS BY BILLY DELFS

DNE-TWO

For years, Dr. Karen, laffe kent her diagnosis a secret

For years, Dr. Karen Jaffe kept her diagnosis a secret.

Today, she delivers a knockout approach to Parkinson's.

AREN JAFFE is all warmed up. On a chilly winter day in the suburbs of Cleveland, she pounds a speed bag as tiny beads of sweat form beneath her blonde bangs. "Sometimes it just feels really good to hit something hard," she says, laughing.

Jaffe admits that when she was first diagnosed with Parkinson's in 2008 at age 49, she was caught off guard and retreated to her corner. Today, she's pulling no punches about the disease.

She's working out at InMotion, the new exercise facility she helped found for people with Parkinson's disease. The bright, airy studio opened its doors in March 2015. Large windows allow natural light to pour in, creating a sunny atmosphere where people with Parkinson's can thrive. "Many of us spent years hiding, worried and afraid, with no one to talk to," she says. "This is a place where people with Parkinson's can find community and tools to empower themselves."

Jaffe knows what it's like to hide from the stigma of Parkinson's. At the time of her diagnosis, she was an ob-gyn in a busy private practice. Fearing her patients' reactions, she hid her condition from all but her husband, Marc, and their three daughters. The family kept her secret for the next three years.

STANDING UP AGAINST STIGMA

Withholding the truth during those years proved difficult—especially for Jaffe's three teenage daughters. Although she emphasizes that it's a very personal decision, she now regrets keeping her PD a secret. "When I finally decided to tell, my skills as a surgeon were in question when they weren't previously," she says. By hiding her disease, she realized she perpetuated the stigma. "One of the bravest things I ever did was to decide that I would be a working surgeon with Parkinson's disease."

Jaffe continued to work for another three years, seeing as many as 35 patients a day and delivering dozens of babies. She found her patients to be overwhelmingly accepting and supportive.

Owning her diagnosis also gave her a powerful voice for the Parkinson's community. In 2011, she and her comedian/writer husband Marc Jaffe founded Shaking With Laughter. Their events have raised almost \$700,000 for Parkinson's research.

InMotion is just the latest expression of Jaffe's passion for helping people with PD. Cycling, tai chi, boxing, dance and more are scaled to accommodate even those who are in wheelchairs. It also offers Delay the Disease classes, an OhioHealth









fitness program that helps people with Parkinson's optimize their physical function. The activities were created in collaboration with movement disorder specialists and fitness coaches. Best of all, the classes are free.

The facility also provides a wealth of information about Parkinson's disease and other movement disorders, and serves as a clearinghouse for health and wellness resources in the Cleveland area. "We provide a place where people can come and find friendship and information so they can live well," Jaffe says. "They don't have to have the stigma and the silence."

Jaffe has more time to devote to InMotion since retiring from her medical practice last year—if you call active involvement in two busy nonprofit organizations retirement. "I loved being a physician and delivering babies, but I love this phase in my life," she says. "I love being able to make a difference in the lives of people with Parkinson's. I feel lucky that this is a part of my journey."

Going the Distance
PD patient, retired
ob-gyn and
InMotion wellness
center co-founder
Karen Jaffe has
learned to speak up
about Parkinson's—
to the benefit of

others.





he nutritional challenges that come with Parkinson's disease can be difficult to navigate, but balanced eating can aid in maintaining energy levels and a healthy digestive system.

According to registered dietitian Lauren Antonucci, owner/director of Nutrition Energy in New York, "By including protein and soluble fiber (fruits, veggies, legumes and beans) with all meals, you can balance out many undesirable common side effects of medications."

Antonucci's advice is to balance protein intake by eating three to four ounces of it two or three times a day. She also says to limit sugar and salt intake, maintain a high-fiber diet, and drink water throughout the day. The appetizing meal here, from recipes by Jess Cerra, personal chef and owner of Fit Food by Jess in Encinitas, California, offers foods that are ideal for those with PD.

Farro and Vegetable Salad

This Middle Eastern grain is not only dense in two of the major macronutrients needed for a balanced diet—carbohydrates and protein—it's also easily digestible.

The symptoms of Parkinson's could have an effect on your appetite and motivation to prepare meals. If you feel too tired to cook, note that cooked farro keeps in the fridge for five days and is easy to toss into salads. Frozen veggies can be substituted for fresh varieties, too.

Fettuccine with Squash Ribbons and Tomatoes

If available (they peak in the summer), heirloom tomatoes are popular delicacies that create a bright and fresh sauce for this easily digestible fettuccine dish.

Precooked sausages are a convenient and flavorful protein source, and can also be easily eliminated from dishes if your doctor has recommended that you lower your protein intake.

Peach or Berry Crisp

This crisp incorporates more fruit into the dessert to increase fiber intake, and also boasts healthy fats from the nuts.

You can use peaches, apples or pears, or substitute three cups berries (fresh or frozen).



Get recipes

for these dishes and more at our Facebook page. Join 75,000 others for news, updates and inspiration.

Facebook.com/ ParkinsonsMore ThanMotion

NOTE

We recommend that you consult with your doctor about your diet and speak to a nutritionist for further guidance.

YOUR 8 THINGS TO REMEMBER

Here are your takeaway tips from this issue of *More than Motion*. Clip and save, or take this page to your next doctor's visit.



Find support online in the lively Parkinson's community. **Read blogs** and follow patients and caregivers on social media for uplifting inspiration.



Registered dietitian Lauren Antonucci suggests eating three to four ounces of **protein** about two or three times a day for a balanced intake. And, of course, drink water.



2 Volunteer to participate in a clinical trial with The Michael J. Fox Trial Finder. Not every trial is right for every person. Find one that's right for you.



6 Dr. Karen Jaffe kept her PD diagnosis a secret for years. It was only after she started telling people about it that she realized what a difference she could make.



A design specialist can give tips for safety and enhanced livability in your home. Read tips from architect Barbara Bouza on how to fix up your home.



Too tired to cook at the end of the day?

Make a batch of farro to use in salads for days, or sub in frozen veggies for fresh ones.

This will save you time and energy later.

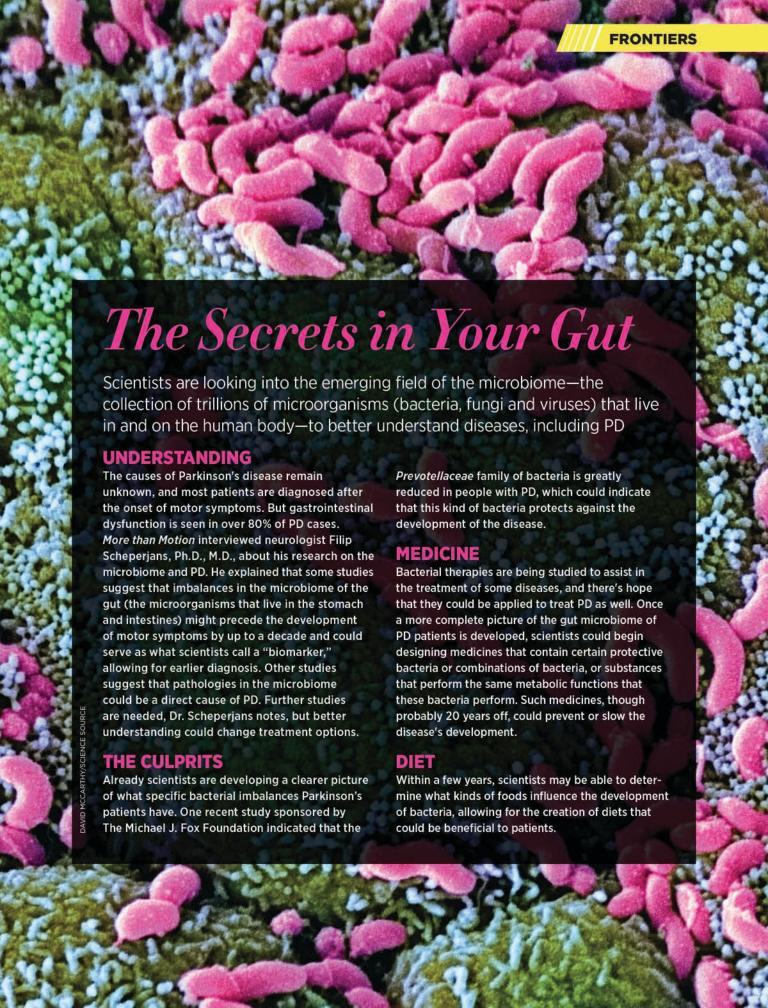


Bundle loose cords to help clear clutter, and look for furniture with locking wheels that can be easily moved and stabilized.



A host of new apps can help caregivers organize and streamline doctor's appointments, medications and more. Search "Parkinson's" next time you look for apps.

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CLICKFOR 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.

3 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



ABOUT US

UCB, Inc. is a patient-centric pharmaceutical company. We are committed to raising awareness of Parkinson's disease through education of patients, caregivers and the wider community.