

Parkinson's Disease and Movement Disorders Center

Parkinson's Update

Northwestern University Feinberg School of Medicine

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Surgical Treatment of Parkinson's Disease

By Avram Frait, MD, MS

Early symptoms of Parkinson's disease are typically well controlled with exercise and medication. Unfortunately, as the disease progresses, these interventions become less helpful; because medication doses are increased over time, many people start to develop intolerable side effects. This stage of the disease is often marked by dose failures, sudden "off" periods, and dyskinesia (movement impairment). This is also the time when surgical treatment—known as deep brain stimulation, or DBS—may be a good option.

DBS was approved by the FDA in 2002 to treat Parkinson's. It involves surgically implanting a metal electrode into a specific area of the brain. The electrode is attached to a battery under the skin of the chest. When the battery is turned on and stimulation begins, the symptoms of Parkinson's improve dramatically, and medication doses can often be significantly reduced.

Not all people with Parkinson's are perfect candidates for DBS, so patients must be selected carefully to optimize their postsurgical outcomes. The ideal candidates have had a robust response to levodopa. If people have improved symptoms of tremor, slowness, and stiffness and experience improvements in balance when they take levodopa, these symptoms should also improve with DBS.

Even patients whose tremor does not respond to medication should expect better tremor control after the surgery than they have ever had before.

An important part of the presurgical evaluation is cognitive testing. Some evidence shows that DBS for Parkinson's can cause deterioration in speech and memory function. Therefore, all patients undergo formal neuropsychological testing to ensure that their cognitive abilities are strong enough to withstand the surgery's effects.

Whether symptoms are well controlled with medication or medication intolerance has developed, it's never too early to ask your neurologist about DBS. For many patients, it is a truly life-changing intervention.



Avram Frait splits his time between Lake Forest Hospital and the downtown campus. He has a specific interest in deep brain stimulation as treatment for Parkinson's disease, essential tremor, and dystonia.

April is **Parkinson's Awareness** Month

Parkinson's disease is a slowly progressing disorder of the nervous system marked by slowness of movement, tremor at rest, muscle stiffness, and problems with gait.

- 60,000 people are diagnosed with PD each year.
- 1 in 100 people over age 60 have PD.
- Men are 1½ times more likely than women to have PD.
- Exercise is vital in managing PD.
- The causes of PD are unknown.

Join us in our efforts to combat Parkinson's disease.

- Get the latest information about PD from our center at parkinsons.nm.org or from our partner, the Parkinson's Foundation, at parkinson.org.
- Share what you've learned with your family, friends, and community.
- Make an impact. Donations are gratefully accepted at 312-926-2033. Our representative will ensure your gift is designated for the Parkinson's Disease and Movement Disorders Center.

PARTNERING WITH PF



CENTER OF EXCELLENCE

The Northwestern Medicine Parkinson's Disease and Movement Disorders Center, recognized by the Parkinson's Foundation as a Center of Excellence, collaborates with the foundation on such initiatives as conferences, professional training, and the annual Moving Day Chicago fundraiser.

Founded in 1957 and based in Miami, the foundation is an international organization that funds research and provides support services, educational outreach, and advocacy for people with Parkinson's disease and their loved ones. Its Centers of Excellence must provide the highest quality in patient care, implement best practices, provide leadership in developing targeted research to extend knowledge of PD, and create innovative models of education, services, and outreach.

Northwestern and the Parkinson's Foundation work together to deliver high-quality patient care, form a united front against Parkinson's, and make a difference.

For more information, visit parkinson.org.

Parkinson's Disease and Movement Disorders Program at the Shirley Ryan AbilityLab

The Parkinson's Disease and Movement Disorders program at the Shirley Ryan AbilityLab provides comprehensive and personalized care in neuro-rehabilitation for people with Parkinson's disease and other movement disorders. Ranked as the top rehabilitation hospital in America by *U.S. News & World Report* every year since 1991, the Shirley Ryan AbilityLab continues to set the standard of care with its science-driven, patient-centered approach. The PDMD program offers comprehensive clinical visits, customized early-stage PD evaluations, individualized outpatient rehabilitation therapy services, fitness center classes, educational sessions, and a broad range of research opportunities.

The interdisciplinary PDMD team works to enhance the abilities and well-being of patients through integrative clinical care, research, education, and community outreach. The team includes physicians, movement disorders specialists, physical medicine and rehabilitation specialists, physical therapists, occupational therapists, speech therapists, nurses, neuropsychologists, nutritionists, and researchers. The program works with patients to create a customized plan, whether focusing on gait, balance, communication, and activities of daily living, or the cognitive, behavioral, and emotional symptoms that can affect well-being and quality of life.



Joining the Shirley Ryan AbilityLab as the PDMD section chief and Northwestern's Feinberg School of Medicine as professor of physical medicine and rehabilitation and of neurology is Jennifer G. Goldman, MD, MS. A movement disorders neurologist, she previously served for 15 years on the faculty of Rush University Medical Center. Goldman is an internationally recognized expert in the field of clinical, research, and educational work on integrated, interdisciplinary patient care and the cognitive and behavioral features of PD and movement disorders.



The PDMD program also welcomes Sharon Marchbanks, PT, DPT, NCS, as program manager. Marchbanks brings to the position her experience as a physical therapist at the Shirley Ryan AbilityLab and previously at the University of Southern California, along with her passion for patient care and education.

Our Journey with Parkinson's Disease

By Claire Pensyl

Ira and I began practicing law together in 1985. We married in 2006. We expected to scale back our law practice and travel the world. Instead, after Ira's 2008 surgery for spinal stenosis, his osteoarthritis became severe, and in 2010 he was diagnosed with Parkinson's. This was in the days when your neurologist told you to exercise but did not say to "exercise, exercise, exercise as hard as you can." Yet even with light exercise at the health club, Ira developed a chronic hamstring injury.

In May 2016 I thought Ira had had a stroke. It was probably dehydration, but I spent four nights in the hospital with him, and then he was in a skilled nursing facility for 36 days. Ira did not receive physical therapy during that time, and we both learned a lot about Parkinson's hallucinations, delusions, and psychosis. We agreed that this setback was not going to happen again. Our strategy was to exercise more, socialize, learn as much as we could about Parkinson's disease, and use every resource available to us.

First and foremost, we responded as a team. We have a few advantages. I am considerably younger than Ira, and he is neither tall nor heavy. On the other hand, he uses a walker and sometimes needs a transport chair to navigate our home. He needs my assistance with many daily tasks and some of his home exercises.

As part of our strategy, we began attending a twice-weekly seated-exercise class close to our home. Most spouses and caregivers also participate in the class, so Ira gets exercise and I do too. For me every class is a respite. For an hour I can pay attention to Ira or choose not to, as more than a dozen people are keeping an eye on him.

We have found friendship and support in the Parkinson's community. Once, I said, "I've lost my sense of humor today. It's gone missing." I received sympathetic smiles and nods from two women. A third woman laughed and said, "Oh, that happens to all of us!" Sense of humor restored. This group is very cohesive, and we look for any excuse to have a potluck lunch or birthday celebration.

Over time, Ira and I increased to four or five exercise classes a week. People often comment on how Ira has improved, knowing how long and hard he has worked for it. At two of these classes, the care partners typically meet to chat as an informal support group. Ira gets his exercise, and I have made two fabulous friends. We check in by phone during the week. Even though we are utterly unlike, we have come to rely on one another. Three of the couples even try to go out for dinner every so often to socialize.

We have been active and have come to love the Hubbard Street dance class. Even though we can't participate anymore, we stay in touch with our cohort and the two care partners we met there.

As part of our goal to remain engaged, we have taken four sequences of Improv for the Parkinson's Community at Second City. Improv is not what we expected it to be. It's not intimidating; you don't have to be funny. But it challenges you to think on your feet, turn on a dime, and keep everyone in the room in your line of vision. We laugh a lot. We get the same sort of high that many people get from the Rock Steady Boxing class. We are both quite fascinated with a new program incorporating improv exercise and LSVT BIG and LOUD into a new communication class led by Pam Palmentera, LCSW.

Recently, instead of just fighting decline, Ira has chosen to be more proactive. He does breathing, speech, vision, and physical exercises at home every morning. Ira also works with personal trainers specifically on his balance and walking. This gives me another respite; when he is with a personal trainer, I climb on a treadmill and listen to podcasts. When a trainer works with him at our home, I can disappear and read.

Ira participated in the Davis Phinney Foundation Sidekicks program, which paired him with a Boy Scout from Barrington to engage in a variety of art projects and general conversation about life. I am currently participating in a Davis Phinney-sponsored interactive online course, Balanced Resilience for Family Care Partners of Those Living with Parkinson's.

We participated in a cognitive behavioral therapy class with Danielle Marino, LCSW. It was a game changer, and we are both happier for it. We've attended three of Pam Palmentera's "Mindfulness on the Go" presentations, and some of her reminders frequently ring in my ears. We also benefited from a class at Northwestern's audiology clinic that has helped us address issues involving a person with Parkinson's and a person with hearing loss and hearing aids.

We heard Angela Roberts, PhD, give seminars about her research on the Speechvive device. When she said it was now commercially available, we jumped at it, and Ira is currently wearing the Speechvive on a trial basis. The jury is still out, but I am spending a lot less time saying "I can't hear you." A presentation by Danny Bega, MD, helped Ira acknowledge that it was probably time for him to stop driving.

We will use any device or service that helps us. Ira gets Botox shots to reduce his drooling. I see a physiatrist to be proactive about the aches and strains of lifting and pushing a transport chair. After an incident at our favorite restaurant, we decided to use a wheelchair in the outside world. This lets us keep doing everything we want to do. Our physiatrist commented laconically, "Probably get there faster, too."

When making restaurant reservations, we request a quiet table and note that we will arrive with a wheelchair but transfer to a restaurant chair. We have become connoisseurs of angled disabled parking spaces and single-user restrooms. One theater manager has indicated on our electronic record that we must always be seated in an accessible row. She also arranges for an usher to take Ira to the men's room. When the accommodations we need aren't available, we create them. In most circumstances I no longer worry about our barging into a women's restroom so I can take Ira to the disabled stall. Often someone outside the stall will ask if we need assistance rather than being offended by our presence.



We have developed a web of professional help. Our core team consists of our physiatrist, neurologist, and physical therapist, plus a speech therapist who comes to our house. We have a regular ophthalmologist, a neuro-ophthalmologist, and a developmental ophthalmologist. A reading therapist helps Ira get both eyes' muscles working with his prism reading glasses. We have benefited enormously from social workers—taking advantage of educational materials, workshops, and support groups. Most important, they have provided a listening ear. Their beneficial insights sometimes completely change our perspective.

Mainly, we try to be patient with each other. Ira cannot assist with most household tasks, but he cleans the kitchen counters and folds laundry. I have developed a habit of keeping a mental list of small chores that can be accomplished while I am waiting for Ira. We try to have alone time and spend part of the day apart—either going to separate rooms at home or sitting separately at the local library for a couple hours.

In late 2017 Ira became seriously dehydrated. After seven hours in the emergency room, I begged the attending physician to let Ira go home, and he agreed, even though he thought Ira had a touch of pneumonia. As it turned out, it wasn't pneumonia but another chronic degenerative disease. Within 90 days Ira had another dehydration episode. We called 911, and the paramedics started a saline drip while he was in the ambulance. He was 80 percent recovered by the time he reached a cubicle in the ER, and we were home in less than three hours. We are now much better at making sure that Ira stays hydrated. You're always learning with Parkinson's.

We keep an eye out for clinical trials. We both participate in Fox Insight and find it a good opportunity to reflect on how things are going. We have both participated in several clinical trials

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Parkinson's Progress

By Bill Grimes

Once the kids cleared out, I climbed onto the foam raft anchored in shallow water off the beach at Union Pier, Michigan. I was in my mid-50s at the time. Standing on the constantly moving raft was usually a fun test of balance and agility. I didn't have much trouble getting on, but standing was a different story. I couldn't do it. I was more puzzled than concerned. Though now middle-aged, I was in good shape, and I'd been athletic all my life. I felt I should have been able to stand on the raft.

I noticed something else around this time: my legs began to feel sluggish and heavy when I got out of bed in the morning. While walking to get coffee with my wife, I asked if she noticed me shuffling. She said no. I told her I was really having to concentrate to put one foot in front of the other.

It was time to see a neurologist, and I was referred to Cindy Zadikoff at Northwestern Medicine. She examined me in November 2009, watching me walk up and down the hall and testing reflexes and balance. She noticed, among other things, that my right arm did not sway when I walked.

Dr. Zadikoff said I had early-onset Parkinson's, a "progressive" disease. I found the term odd. I consider "progressive" a positive term; Parkinson's is anything but positive.

There is no cure for PD, but exercise can slow its progression. I had been taking Requip for restless legs syndrome for years; it can also reduce the symptoms of PD, so Dr. Zadikoff increased my dose. I intensified my exercise and physical activity, including biking, free weights, push-ups, boxing, yoga, climbing stairs, golf, playing catch with my son, even ballet lessons—so generously offered to people with Parkinson's by Hubbard Street Dance Chicago.

I was mobile enough to keep working for several more years, though difficulties with concentration and fatigue began to affect my work around 2010. A limp in my right leg and a tremor in my right hand became noticeable in 2011. In 2012, every task—physical and mental—began to take longer. Fingers,



especially on my right hand, were no longer as responsive. Even though I'm right-handed, I began using a mouse with my left hand. I stopped writing longhand because my handwriting was not legible. Balance was a constant issue.

The biggest problem was freezing gait. It's as difficult to describe as it is to treat. In a standing position, I often have difficulty getting my legs to obey instructions from my brain to walk. Oddly, it's never a problem walking up or down stairs, only on flat ground.

Dr. Zadikoff prescribed carbidopa and levodopa in 2012, but as the Parkinson's progressed, gaps in the medications' effectiveness became apparent. I took medication every three hours, but it only lasted about two. I became more dependent on a knee walker to bridge the gaps between doses. I was not comfortable leaving home for fear I would become immobile while away.

Dr. Zadikoff suggested I try some experimental drug treatments. I've participated in several studies, and the last has greatly improved my quality of life. I am mobile for about 12 hours a day.

Will I ever be able to stand up on the big foam raft again? Perhaps, as I did manage to go stand-up paddleboarding last fall during the weekend of my daughter's wedding in Hawaii.

When to Disclose

By Emily Zivin, MSW, LCSW

A Parkinson's diagnosis can be very difficult, and everyone experiences it differently. Some people involve their families in their medical treatment from the beginning, while others are more private. Whatever your choice, learning to live with PD creates a new normal.

Deciding when to let people know about your PD diagnosis is a personal choice, and deciding how and when to inform your spouse, children, and friends can cause a great deal of stress. Being prepared can help with these difficult conversations.

It's important to remember that you don't have to disclose your diagnosis until you're ready. However, with time, your symptoms may become more pronounced, so once you're prepared, you may want to inform your family and other people who see you often.

Many symptoms are observable, and friends, neighbors, and children will probably notice these changes. Informing them about your diagnosis will prevent them from making incorrect assumptions. Think about how much information to disclose, as what you tell an adult and a child may be different.

It's not necessary to discuss all the details, but you'll want to include information about your specific diagnosis and how you're handling it. Letting loved ones know that you're prepared for what will happen in the future and how it will affect them is an important conversation.

If your spouse or partner was not present at the time of diagnosis, consider disclosing as soon as possible. As a team, you should learn about Parkinson's disease: ask questions at your doctor appointments, read books, and reach out to local Parkinson's disease organizations and support groups. Together you can plan for the future. Take as much time as you need to learn about the disease and treatment options.

Emily Zivin is the project lead for the Parkinson's Wellness Initiative. She can be reached at emily.zivin@northwestern.edu or 773-516-5864.

Our Journey with Parkinson's Disease

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and are currently in a trial investigating a new model of delivering care to people with advanced Parkinson's.

Our lives are not all about Parkinson's. We live in Wilmette and attend many music and theater events at Northwestern University and other venues that offer valet or otherwise easy parking. We have our favorite accessible movie theaters for viewing Met Opera HD or National Theatre Live performances. We have read *Don Quixote*, *Moby Dick*, and *The Brothers Karamazov* with a book group at the Evanston Public Library. With another group, we are reading and seeing Chekhov's plays this year. I read 100 books in 2018, although I probably don't remember some of them. I get cranky if I don't finish my *New Yorker* the week I receive it. We argue every Sunday over how much time Ira is allowed for finishing the first section of the *New York Times*. Ira often says "thank you" and "I love you." I try to reciprocate.

We find our Parkinson's-centric life intellectually interesting and socially beneficial. Ira may have Parkinson's, but we both think we've got it pretty good.

Support Groups, Programs, and Events

Chicago

Monthly Parkinson's Disease Support Group

251 East Huron Street, Feinberg Pavilion, Room A

First Tuesday of the month

312-503-4397 for more information

Dance/music therapy and movement:

10:30 a.m.

Group physical therapy: 11:15 a.m.

Provided box lunch: noon

Guest speaker: 1 p.m.

Care Partner Support Group

250 East Superior Street, Prentice Pavilion, Room Q

Second Tuesday of the month,

3:30–4:30 p.m.

312-503-4397 for more information

Parkinson's Disease 101

250 East Superior Street, Prentice Pavilion, Room P

First Wednesday of the month, 3–4:30 p.m.

Registration required; contact Carolyn

Taylor, APN, at 312-695-1822

Art and Yoga

250 East Superior Street, Prentice Pavilion, Room Q

Second, third, fourth, and fifth Tuesdays of the month

Art therapy: 1–2 p.m.

Yoga: 2–3 p.m.

Empowering You through Parkinson's: Cognitive Behavioral Skills for Reducing Anxiety and Depression in Parkinson's

259 East Erie Street, Lavin Family Pavilion, 13th-floor conference room

For information and to register, contact

Danielle Marino, LCSW, at 312-695-2168.

PARKINSON'S WELLNESS INITIATIVE

\$40 monthly fee

Contact Emily Zivin, LCSW, at 773-516-5864 for more information.

This program is supported by a community grant from the Parkinson's Foundation.

Bernard Horwich JCC

3003 West Touhy Avenue

Support Group for PD:

First Tuesday of the month,

7:30–8:30 p.m.

EXERCISE CLASSES

Strength and Balance:

Mondays, 3–4 p.m.

Nia for Parkinson's:

Tuesdays, 10:30–11:30 a.m.

Strength and Balance:

Wednesdays, 3–4 p.m.

Hyde Park JCC

5200 South Hyde Park Avenue

Support Group for PD:

Second Wednesday of the month, 10:30–11:30 a.m.

EXERCISE CLASSES

Silver Sneakers: Mondays, Wednesdays, and Fridays, 9–10 a.m.

PD Strength and Balance:

Tuesdays, 11 a.m.–noon

Suburbs

Improve Communication Using Improv and LSVT for Those with Parkinson's and Their Care Partners

Series alternates between Lake Forest Hospital and Northwestern Memorial Hospital.

Next series of eight sessions will be in Lake Forest beginning in April.

For more information, contact Linda Egan at 847-535-8244 or Pamela Palmentera, LCSW, at 312-503-4397.

Support Group

NM Lake Forest Fitness Center

1200 North Westmoreland Road, Lake Forest

Second Wednesday of the month,

10 a.m.–noon

Fitness Classes

NM Lake Forest Fitness Center

1200 North Westmoreland Road, Lake Forest

Lindenhurst Health and Fitness Center

3098 Falling Waters Boulevard, Lindenhurst

Call 847-535-7000 or visit lakeforesthfc.com/parkinsons-programming for details.

Pedal for Parkinson's, levels 1 and 2

RX for Parkinson's, levels 1 and 2

Pilates for Parkinson's, levels 2 and 3

Strength and Balance, levels 2 and 3

Dance for Parkinson's, levels 3 and 4

Functional Fitness, levels 3 and 4

Yoga for Parkinson's, levels 3 and 4

Rock Steady Boxing, all levels

Bringing Care into the Home: Geriatric Medicine Home Care

By Katherine O'Brien, MD

Advancing Parkinson's disease is associated with falls, worsening motor symptoms, and more difficulty with daily tasks (such as using the bathroom and getting out of bed). Many people with PD also have other medical problems and take multiple medications. Some visit the hospital more often and begin to have trouble getting to a clinic to see their doctors. Hospitalizations can lead to confusion and long recovery times for those who are already weakened from chronic diseases.

These realities can place a strain on people with Parkinson's as well as their family and friends who care for them. Home-based care is one way to reduce travel to a clinic or hospital. Studies have shown that home-based care is also successful at reducing hospitalizations and promoting patient goals and satisfaction.

At Northwestern Medicine, we have created a new home-care medicine program, led by Dwayne Dobuschetz, NP, and me. We see people throughout Chicago in their places of residence, including homes, independent and assisted living facilities, and dementia-care units. We coordinate and work with a person's established medical team to create the best plan of care. Just like a regular clinic visit, the cost of home-based care is generally covered by insurance. The program's goal is to bring more care into the community, helping people stay in their homes and avoid hospitalizations.

To learn more, call 312-695-2619.

Katherine O'Brien is the physician for the Northwestern Home Care Medicine central region practice, an associate medical director for JourneyCare hospice, and an assistant professor of medicine at Feinberg School of Medicine. She participates in both the geriatric and palliative medicine consulting services at Northwestern Memorial Hospital. Her clinical interests include home care, frailty, advanced care planning, and end-of-life care.

Meet the Staff

Danielle Larson, MD



Originally from Minnesota, Danielle Larson was raised overseas and attended medical school at Boston's Tufts University.

She completed her neurology residency at Northwestern University, where she served as the quality improvement and patient safety liaison. Larson was excited to stay at Northwestern for a two-year fellowship in movement disorders that has allowed her to continue her research on exercise and quality of life in Parkinson's patients. She has also found a passion for patient care and research in Huntington's disease.

Support Group: Lost and Found

By Susan Krueger

It took me over a dozen years to get to a support group. I was afraid that I might see my future and find it daunting. In addition, my mental picture of a meeting included a circle of very sad people. I had managed to beat the odds and avoid depression thus far. Not wanting to press my luck, I told myself I was doing well enough on my own.

I asked my neurologist if he had any patients who attended a support group. He wasn't sure. I asked his

opinion. He said they are good for some, not for others; some groups are helpful, some aren't. Not much help there. So my avoidance persisted.

I continued to read PD how-to manuals, articles, and blogs. There was enough about support groups to pique my interest. I attended a Partners in Parkinson's event. The camaraderie at the tables and in the breakout rooms was surprising. Sharing was easy and sincere. One session featured a man who had launched a support group and served as its facilitator. He seemed positive—almost fun. Could this be possible? There was a panel discussion featuring doctors and others with impressive credentials, plus a man who was listed as a “person with Parkinson's.” He was in a support group. Guess who answered the most questions in that session? Yep, the PWP. I discovered there was a lot to be learned from a peer.

I was finally ready to try exploring, when I stumbled upon a group in Lake Forest. I took a deep breath and gave it a chance.

There was a lovely person leading it. I liked her immediately. The atmosphere was warm and informal. The participants were positive and yet realistic. There were people at all stages with different combinations of symptoms. I left feeling good. Fears of depression assuaged, I decided to come back the next month.

At the end of that session, the coordinator asked me if I'd be interested in leading the PD care-and-share portion of the meeting—and well over two years later, with a new coordinator and a lot more folks in the group, I am still happily in that role.

When you help someone else, the blessing comes straight back to you.

My key discoveries:

- We come from a variety of backgrounds. Parkinson's immediately levels the playing field.
- We don't have all the answers, but we can empathize. It's important to know that people understand and care.
- We do have some of the answers! We have valuable insights to share that can truly help others, which is emotionally rewarding.
- We all prefer to feel positive. Sometimes we need to be encouraged, and we stand ready to encourage others.
- It's never too late to improve the hand that PD has dealt. You can improve your quality of life starting today.
- There is a spark inside each of us. It can light your whole being. The “true you” is still in there, and when we catch a glimpse, it is a beautiful thing. A support group has people who help you rediscover your spark.

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- The PD mask is fragile—it can be shattered with a smile!
 - A healthy sense of humor smooths a bumpy road.

If things are going well for you, then you have hope to give! Your well-placed enthusiasm could make all the difference for someone. It's the "if they can do it, I can do it" effect. When you help someone else, the blessing comes straight back to you.

But if you find yourself in a slump, at the very least you'll find people who can understand your pain and empathize. There are good listeners and encouragers, and they may be able to provide resources that truly help.

I can only speak for Northwestern Medicine's Lake Forest Hospital PD Support Group. I got lucky with the first group I tried. Our coordinator, Linda Egan, is well suited to her role. Every month she lines up quality speakers to educate us on pertinent topics. She follows up tenaciously to track down answers to our questions and solutions to our issues. It is an engaging, well-run, professional meeting.

During the care-and-share portion, you will always have a chance to bring a question to the whole group. We'll listen to your challenges, share possible work-arounds, and celebrate successes with you. There will be thought-provoking discussions along the way.

Don't be a late adopter like me. If you are interested in exploring the benefits of joining a support group, I encourage you to try one soon. It is my hope that you find one that feels just right.



Susan Krueger was diagnosed with PD in 2003 after experiencing a tremor in her right hand for about six months. She continued working in corporate positions and consulting for 10 years before retiring. As a volunteer

with the Northwestern Medicine–Lake Forest Hospital PD Support Group, Krueger works hand in hand with the program coordinator, selecting topics and facilitating discussion on the PD side of the monthly meeting's care-and-share portion. She also helps with communication and maintaining contacts.

Believing that exercise is key to living your best life with PD, Krueger works out and attends classes four to five times per week at Northwestern Medicine's Lindenhurst Health and Fitness Center. She and her husband, Tom, live near their son Matt, daughter-in-law Katy, and grandchildren Chloe and Charlotte. Krueger's other interests include flower gardening, antiques, flea markets, time with friends, and trips "up north" to Wisconsin. She credits her faith, her supportive husband and family, solid friendships, positive attitude, and good medical care for keeping her able to enjoy life despite PD.

Feeling Stuck in Your Caregiving Routine?

Simple, low-cost solutions to support caregivers

By Claudia Cook, MSW

It's easy to think we can and should do it all when it comes to caregiving, but at what personal, physical, mental, emotional, or financial costs? Fortunately, many creative and innovative solutions can help you. Choose one or two and see how they work.

Online helping hands

Many people you know have probably offered or would be willing to help—friends, family, neighbors, and professionals. Have you taken them up on it lately? It feels good to give to others, but sometimes it's hard to receive. One website that makes asking for and scheduling help easier is www.LotsaHelpingHands.com. This free online community allows you to request assistance with tasks such as preparing meals, accompanying your loved one to doctor's appointments, running errands, or companionship. You identify tasks, create a schedule, and invite the people you may want to help. The site sends reminders so nothing falls through the cracks. You can also use this community as a centralized location for well wishes and updates. Go ahead, create a community. Allow others to feel good helping you out.

Paid caregiving

There may be some tasks that you feel uncomfortable asking friends or family to help with. You can hire caregivers to assist with such tasks as bathing, toileting, dressing, transferring, cooking, errands, housekeeping, and companionship. There is typically a 4-hour minimum shift, with 12-hour maximums; live-in care is another option. Hourly rates in Chicago average \$25–\$29, while live-in caregivers are approximately \$275–\$350 per day.

It's best to hire a caregiver through a licensed home care agency. You can find caregivers through word of mouth or by contacting the Parkinson's Disease and Movement Disorders Center at 312-503-4397 or ppalment@nm.org. You can also contact your local Area Agency on Aging (312-743-0300 for Chicago, 708-383-0258 for suburban Cook County) for a list of vetted agencies.

They can also provide questions to ask when hiring a caregiver and advice on ways to control the cost. US military veterans can call 800-437-9824.

If you want to hire a caregiver but feel uneasy having a stranger in your home, an easy solution is a security camera. Many cameras allow you to see what's going on via an app on your smartphone. (Of course, you'll want your loved one's and caregiver's permission to do this.) Cameras can be purchased at retailers such as Amazon or Best Buy for under \$75. You can even use them to check in when you run errands and leave your loved one at home alone.

Adult day care

Another approach to daily assistance is an adult day care center (ADC). These centers provide supervision and care to seniors and people with dementia in a structured setting, allowing you to go to work or take a break from your caregiving responsibilities. Many provide transportation to and from the center at no cost or on a per-ride basis. Traditional ADCs provide structured social and recreational activities, meals, and basic health services. When compared with home care, ADCs usually cost at least 50 percent less. In 2018, the average daily rate for ADCs nationwide was \$70. Search online to find an ADC near you and then take a tour to see if it's a good fit.

Safety and medication-management products

If your loved one lives alone and you worry about safety, some low-cost and easy-to-use products can give you peace of mind. Motion sensors placed strategically around the house will passively monitor activity. If there is unusual (or an absence of) activity, you'll receive a notification so you can respond appropriately. You can be alerted if someone doesn't get out of bed or hasn't opened the refrigerator, spends too much time in the bathroom, or doesn't close the front door. TruSense (www.MyTruSense.com) has a passive monitoring starter kit plus additional products for health and safety monitoring.

If you're responsible for medication management, innovative tools and services can simplify the process. MedMinder (www.MedMinder.com) has a mail-delivery pharmacy that will coordinate the transfer of a patient's medications, double-check for medication interactions, sort medications into a tray, and set up electronic reminders. When it's time to take a medication, the pill-dispensing unit will blink. If the meds aren't taken, the device will beep, then call you. If the medication is still not taken, the device will send an alert to your care team via text, email, or phone. It tracks missed medications and creates a report so you can figure out why meds aren't being taken at a certain time and then make adjustments. An additional benefit is the means to passively check in throughout the day at no extra cost. The MedMinder device is billed as a monthly subscription.

Other helpful products include an automatic stove shutoff device, cabinet locks, GPS locator watches, and alarms. Often a simple product can make a big difference.

Cost assistance

As you begin paying for assistance or products, you'll want to look into benefits you may qualify for. There are over 2,500 benefit programs available nationwide. You can determine whether you qualify at www.BenefitsCheckUp.org. There may also be discounts on medications or lab tests. Visit www.NeedyMeds.org and www.PALS-LABS.org.

More help

These suggestions are just a sampling of what's available to lighten your load. If you're feeling overwhelmed with taking the next step, you may want to hire a life-care manager. These professionals, usually social workers or nurses, meet with you and your loved one at home to assess, plan, coordinate, and monitor services to enhance the quality and safety of care. They often

play a crucial role for people whose families don't live nearby. They can check in, accompany patients to doctor visits, and be available when an emergency occurs. Hourly rates are around \$150. Find more information at www.AgingLifeCare.org.

**Sometimes asking for help
is the most meaningful
example of self-reliance.**

—Senator Cory Booker

If you have questions about these solutions, please call Parkinson's Disease and Movement Disorders Center social worker Pamela Palmentera at 312-503-4397 or email ppalment@nm.org. You can also contact the author at 847-470-1703 or ccook@livhome.com.

Claudia Cook is the director of professional services at LivHOME, a national company providing caregiving, care management, and care technology. She is also an adjunct professor in aging at the University of Chicago's School of Social Service Administration.

Please note that Northwestern does not endorse any of these products or services and the article expresses the sole opinion of the author.

Research Participation Opportunities at Northwestern Medicine

The Parkinson's Disease and Movement Disorders Center is grateful for the contributions of our research participants. Consider making a personal contribution to research by participating in a clinical trial. All study-related care is provided at no charge, including

- physician visits and physical examinations
- laboratory services
- study medication

PARKINSON'S DISEASE

Biomarkers Discovery in Parkinsonism

This study investigates how the brain and motor behavior change over time in people with movement disorders and in healthy individuals. Information will be collected through structural and functional MRIs, blood samples, and behavioral motor and cognitive assessments. Participants include people with Parkinson's disease, progressive supranuclear palsy, or multiple system atrophy as well as healthy controls.

FoxBioNet: LRRK2-002: Detection of LRRK2 Activity in Human Biospecimens

The objective is to determine whether LRRK2 gene levels and LRRK2 gene kinase activity differ among LRRK2 PD, idiopathic PD, nonmanifesting LRRK2 mutation carriers, and healthy controls.

Funded by Michael J. Fox Foundation for Parkinson's Research

Motivational Interviewing and Physical Activity Change in Parkinson's Disease

The objective is to evaluate ways to motivate people with Parkinson's disease to increase their physical activity. The study will last six months. Participants will be placed in one of four groups:

- telephone-based motivational interviewing
- web-based application to keep track of activity
- combination of motivational interviewing and web-based application
- educational program on various issues related to Parkinson's disease.

Northwestern Movement Disorders Center Biorepository

The objective is to create a repository of tissue and DNA samples, clinical information, and family medical histories from patients diagnosed with movement disorders, familial controls, and healthy control subjects for use in research to identify factors that either cause these neurologic conditions or increase the risk of developing them. Samples collected include a blood or saliva sample and a skin biopsy. Participants may choose to donate one or both samples.

Resistant Maltodextrin for Gut Microbiome in Parkinson's Disease: Safety and Tolerability Study

This study evaluates the safety and tolerability of a dietary fiber (resistant maltodextrin) in PD patients as well as the fiber's potential effect on gut microbiome, motor functions, and non-motor functions. Half of the study participants will receive resistant maltodextrin and the other half will receive a control substance (maltodextrin).

Study of the Safety, Pharmacokinetics, and Pharmacodynamics of BIIB054 in Subjects with Parkinson's Disease (SPARK)

This study evaluates the safety and potential efficacy of the drug BIIB054 in slowing or reducing Parkinson's disease progression.

This investigational drug targets alpha-synuclein, a molecule associated with Parkinson's disease.

Funded by Biogen MA

Study to Assess the Efficacy, Safety, Pharmacokinetics, and Pharmacodynamics of GZ/SAR402671 in Patients with Early-Stage Parkinson's Disease Carrying a GBA Mutation or Other Prespecified Variant

This study will evaluate the possible risks and effectiveness of the study drug (GZ/SAR402671) in PD patients carrying the GBA gene mutation. In addition, the study will enable a better

understanding of the role of GBA as a risk factor in the development and progression of PD. The effects of the study drug will be compared with those of a placebo, an inactive substance made to look like an active medicine. Participants will receive either the study drug or the placebo.

Funded by Sanofi, US

Study to Define the Safety, Tolerability, Clinical, and Exploratory Biological Activity of the Chronic Administration of Nilotinib in Participants with Parkinson's Disease

The objective is to assess the safety and tolerability of the daily oral administration of the study drug (nilotinib) in moderate/advanced and early/de novo PD patients. Analysis will compare the observed changes in Parkinson's symptoms between baseline and six months. Note: this study is being conducted at Rush University Medical Center.

Funded by Michael J. Fox Foundation for Parkinson's Research

Randomized, Placebo Surgery Controlled, Double-Blinded, Multi-Center, Phase 2 Clinical Trial to Evaluate the Efficacy and Safety of VY-AADC02 in Advanced Parkinson's Disease with Motor Fluctuations

The purpose of this study is to assess the delivery and resulting enzyme activity of VY-AADC02, administered bilaterally to the putamen using CED with MRI guidance, as well as the efficacy and safety of VY-AADC02.

Funded by Voyager Therapeutics

ATAXIA DISEASE

Clinical Trial Readiness for SCA1 and SCA3

The goal is to bridge the gap between the current state of clinical-trial readiness and the optimal one for SCA1 and SCA3 (fatal rare diseases with no treatments). Investigators in the US and Europe will establish cohorts of subjects at the earliest disease stages; validate imaging markers to detect disease onset and early progression, even prior to ataxia onset; and identify clinical trial designs that will generate the most conclusive results on treatment efficacy with small populations of patients.

Phase III, Long-Term, Randomized, Double-Blind, Placebo-Controlled Trial of BHV-4157 in Adult Subjects with Spinocerebellar Ataxia

The study compares the effectiveness of BHV-4157 (200 mg once daily) versus placebo after 48 weeks of treatment in subjects with spinocerebellar ataxia (SCA).

Funded by Biohaven Pharmaceuticals

For more information about participating in clinical trials, please contact the Movement Disorders Research Office at 312-503-0755 or pdclinicaltrials@northwestern.edu.

For more information about Parkinson's disease research at Northwestern, visit www.parkinsons.northwestern.edu/research/index.html.

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PATIENT AND FAMILY SYMPOSIUM

Sunday, April 28

8:30 a.m.–12:30 p.m.

Lake Forest Hospital

1000 North Westmoreland Road

Lake Forest, Illinois

Continental breakfast provided. Sessions include

- "New Treatment Pipeline" with Tanya Simuni, MD
- "PD Genetics" with Niccolo Mencacci, MD, PhD
- "Management of Advanced PD" with Avram Frint, MD
- "Cognitive Changes in PD" with Michael Mercury, PhD
- "Exercise and PD" with Linda Egan, PT

RSVP at 847-535-8244. Registration is free. Space is limited.