Fall/Winter 2025 | Care Partner Issue

Parkinson Report

Parkinson's
Foundation

How to Make the Most of Your Parkinson's Care
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2026 Events

View all upcoming events at **Parkinson.org/Events**.

january

7-11	WALT DISNEY WORLD MARATHON WEEKEND
24-25	MIAMI MARATHON WEEKEND
29-feb 1	DISNEYLAND HALF MARATHON WEEKEND

february

28	PARKINSON'S REVOLUTION Sign up at **Parkinson.org/Revolution**
26-mar 2	DISNEY PRINCESS HALF MARATHON WEEKEND

march

1	TOKYO MARATHON
8	LOS ANGELES MARATHON WEEKEND
11	EXPERT BRIEFING: TREMOR, SHAKES AND EVERYTHING IN BETWEEN: PARKINSON'S MOTOR SYMPTOMS Register: **Parkinson.org/ExpertBriefings**
14	MOVING DAY THE VILLAGES
28	MOVING DAY PALM BEACH

april

PARKINSON'S AWARENESS MONTH

8	EXPERT BRIEFING: THE LATEST ADVANCES IN PD RESEARCH AND TREATMENT Register: **Parkinson.org/ExpertBriefings**
11	MOVING DAY SOUTH ALABAMA
16-20	RUNDISNEY SPRINGTIME SURPRISE WEEKEND
18	MOVING DAY LAS VEGAS MOVING DAY PIEDMONT TRIAD
20	BOSTON MARATHON
25	MOVING DAY BATON ROUGE MOVING DAY KNOXVILLE MOVING DAY VENTURA COUNTY
25-26	EUGENE MARATHON WEEKEND
26	BIG SUR MARATHON WEEKEND MOVING DAY COLUMBUS MOVING DAY KANSAS CITY

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Find answers to your most pressing PD topics through free, expert-led courses.

Parkinson.org/LearningLab

Parkinson's Foundation
Learning Lab

7th WORLD PARKINSON CONGRESS
Phoenix, AZ, USA

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MAY 24–27 2026

Visit WPC2026.org.

KATHLEEN BLAKE, MD, MPH

Update from Our People with Parkinson's Advisory Council Chair

You never know where a life-changing diagnosis will take you. As a retired physician, I loved helping people — and I still do — but now in an entirely new way. My Parkinson's disease (PD) experience has led me to volunteer as Chair of the People with Parkinson's Advisory Council, helping guide Parkinson's Foundation programs to make the biggest impact.

When I was practicing medicine, patients often saved their most important questions for the end. Today, my advice for anyone with PD is to ask your priority questions right away. To me, helping the PD community advocate for their best care is one of the Foundation's most exciting priorities. Learn more on page 4 of this issue.

In addition to physical therapy and exercise, getting involved in the PD community and attending local events like Moving Day and Parkinson's Revolution put the wind back in my sails. One of the most meaningful parts of this journey has been the unwavering support from my husband, Bob Ballance, who is my care partner and co-leader of our local support group. From being my second set of ears at appointments to joining me at Moving Day, he's my anchor.

November is National Family Caregivers Month. We dedicate this issue to care partners — those who witness PD daily, provide support from afar and those who care for themselves. In this issue, we offer tips for long-distance caregiving (page 6), helping a loved one with advanced PD (page 10) and more. Visit **Parkinson.org/CaregiversMonth** for more resources.

KATHLEEN BLAKE, MD, MPH
People with Parkinson's Advisory Council Chair

5 Facts About Parkinson's and Exercise

For those with Parkinson's disease (PD), exercise is a vital component to maintaining balance, mobility and activities of daily living. Here are five facts about PD and exercise:

1. People with Parkinson's who increase physical activity to at least 2.5 hours a week can significantly **improve their quality of life**.

2. To help manage PD symptoms, an **exercise program** should include these key components: aerobic activity, strength training, balance, agility and multitasking, and flexibility.

3. There are many PD-tailored exercise programs that help focus on making movement and daily activities easier. Find a nearby PD exercise class through your local chapter at **Parkinson.org/Chapters**.

4. Exercise has a **neuroprotective effect**. Neuroprotection is when the brain works to prevent the death of neurons, or brain cells, which impact dopamine.

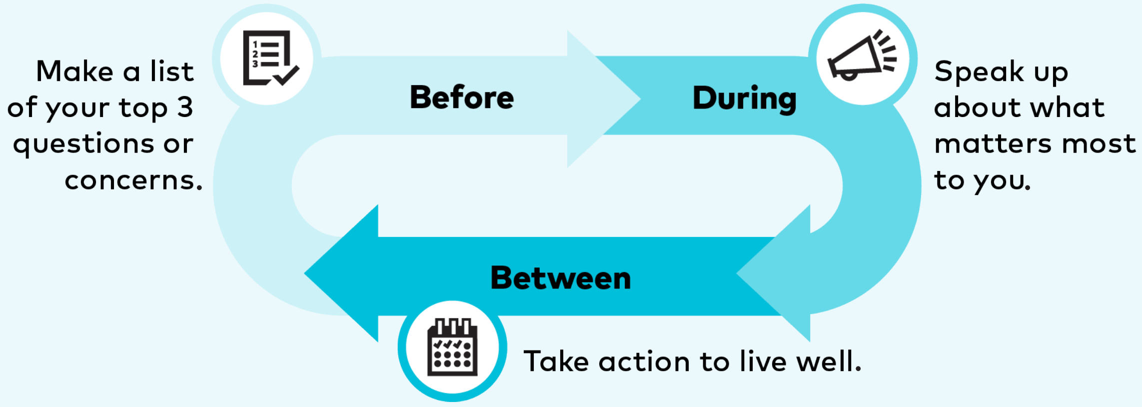
5. Studies show that engaging in any level of physical activity is beneficial for **movement and non-movement PD symptoms** and may improve cognition, depression and fatigue.

Explore more exercise resources at **Parkinson.org/Exercise** and get moving today with virtual PD-tailored fitness videos at **Parkinson.org/PDHealth**.

How to Make the Most of Your Parkinson's Care

Parkinson's disease (PD) appointments can feel overwhelming, but speaking up and advocating for yourself helps you get the most out of every visit. You are a member of your PD healthcare team — your input guides the team in providing the care and treatment that is best for you. Advocating for yourself gets easier with practice.

The PD Appointment Cycle



Before Your Appointment

Decide what you want to talk about with your healthcare team before your appointment. Use your appointment to talk about what's most important to you, such as how PD is impacting your physical health, mental health, work, everyday activities and hobbies.

1. Think about how Parkinson's affects your life.
    - Symptoms: What symptoms bother you most? How do they impact daily life?
    - Goals: What are you focused on right now? For example, staying active or going to a family event might be your priority.
    - Concerns: What are your current worries about PD?

2. Write down your top three discussion topics and bring them to your next appointment.

3. Make a medication list. Include all the medications, vitamins and supplements you take. Include dosage and notes like if the medication is not lasting as long as it used to.

4. Bring someone you trust with you to your appointment. They can take notes, offer another perspective and help review your follow-up steps.

During Your Appointment

Your appointments are about you. Your care team is there to listen and help, but they can only do that if you are open about what is working and what is not.

1. Share the list of your top three discussion topics at the start of your appointment. Be clear and specific. This information can

help your healthcare team adjust current treatments, prescribe new therapies and offer resources or referrals.

2. Ask questions. If something is unclear, ask for clarification.

3. Talk about next steps. Before you leave, ask: "What steps can I take between appointments to help with my symptoms and do the things I love?"

4. Ask for a printed copy of appointment notes or instructions.

Between Appointments

Stay focused on what you can do to live your best life. Your care is an ongoing process. What you do between appointments is just as important as the appointments themselves.

1. Review your notes and handouts. This will help you remember what you discussed with your healthcare team and help you plan next steps.

2. Create an action plan. Create a plan to act on the recommendations you discussed with your team. Write a to-do list with deadlines to stay on track. To kick-start your action plan:
   - Explore Parkinson's resources and support at **Parkinson.org/Resources**.
   - Connect with your local Parkinson's Foundation chapter to find area community events, exercise classes and support groups. Find your chapter at **Parkinson.org/Chapters**.
   - Contact our Helpline at 1-800-4PD-INFO (1-800-473-4636) for referrals to specialists and local exercise and wellness classes.

3. Track your progress.
   - Keep track of how symptoms, medicines and lifestyle changes affect you.
   - Look back at your top three list from your last appointment. Are you feeling better, worse or the same?
   - Keep notes. Use them to prepare for your next appointment, and the cycle starts over again.

Learn more at Parkinson.org/OptimizingCare. For help making the most of your care and preparing for PD appointments, call our Helpline at 1-800-4PD-INFO (1-800-473-4636).

> Early in my PD diagnosis, I learned that self-advocacy is essential. Taking charge of my journey has improved my quality of life. I prepare for my semiannual PD appointments, spending time reflecting and prioritizing what matters most in my life. This helps me better communicate and partner with my healthcare team.
>
> I try to think more holistically about my biggest concerns, not just my motor symptoms but also my emotional and cognitive well-being. Having my spouse join my visits offers another perspective, helps us discuss results and supports follow-through on my care plan.
>
> Self-advocacy doesn't always come naturally, and the Parkinson's Foundation is offering some powerful tools and training to help the community better understand how to build and apply these skills in life with Parkinson's disease.
>
> **- KEN THURMAN, PEOPLE WITH PARKINSON'S ADVISORY COUNCIL MEMBER**
> Living with Parkinson's

Long-distance Caregiving: 8 Tips to Support Your Loved One

Living far away from a loved one with Parkinson's disease (PD) can leave you wondering how to offer meaningful support. However, living out of town does not mean you are not involved or do not care. While there are limitations to long-distance caregiving, there are many ways to help. Here are eight tips to support your loved one from afar:

1. **Learn about Parkinson's.** You will be better able to provide support if you have a basic understanding of the disease. Get started at **Parkinson.org/PDLibrary**.

2. **If you are the primary caregiver, consider hiring a geriatric care manager.** Members of this growing profession can help coordinate financial, legal and medical services, in-home care providers and transportation — and they regularly communicate with family members.

3. **Call every week.** Set a designated day and time and make the call faithfully. Try to use video during calls so you can see each other.

4. **Let the primary care partner know you are there for them.** Keep an open line of communication. Even during tough times, many people do not want to bother their adult children. Directly ask them how you can help — from ordering groceries to planning your next visit.

5. **Talk finances.** Inquire tactfully but clearly. People rarely ask for financial help. If possible, offer to help with household utility bills or home-related services, or to buy a weekly meal, medical products or groceries online.

6. **Send a caregiver gift.** This can be something simple, from a card to a self-care appointment, like a massage. Small acts of kindness can mean a lot for a caregiver going through a trying week.

7. **Visit.** Budget for regular trips to visit your loved one. Plan ahead with the primary care partner so they can plan time for respite. Remember you are there to listen and help. Offer to take over responsibilities during your visit so the primary care partner can take time for themselves.

8. **Have hard conversations early on.** Your loved one's needs will change over time. Have an open conversation with them and the primary care partner about planning for the future, including logistics planning and advance care planning. Help them organize their records and documents.

What NOT to do when caregiving from afar:

- × Don't give up offering to help. There are many ways you can offer support.
- × Never assume that "no news is good news." Check in regularly.
- × Don't forget that thinking and memory changes are part of PD, and difficult to handle.
- × If you visit, don't add to the caregiver's stress level.

Learn more about caregiving from afar at Parkinson.org/CareFromAfar.

How Ripley's Family Makes Caregiving from Afar Work for Them

Parkinson's disease (PD) has reshaped life for everyone in Ripley Fricano Hensley's family. She was in college when her parents told her and her sister about her father's diagnosis. "I knew something was awry, between the mysterious doctors' appointments and cryptic texts," Ripley said.

The news motivated Ripley. As a new nurse, and living 973 miles away from her parents, she began looking for ways to improve care for people with Parkinson's, in and out of the hospital. "I became involved with the Parkinson's Foundation first through their resources for healthcare professionals and care partners, and then as a volunteer," she said.

Within a few months, Ripley completed her first Parkinson's Champions race, cheered on by her family. She volunteered with her local Moving Day committee, which ultimately led to serving on the People with Parkinson's Advisory Council — a group that ensures the voices of people with PD and care partners shape Foundation goals.

In her Council role, Ripley works with the Hospital Care Initiative team to make hospital stays safer for people with Parkinson's. In her long-distance caregiver role, she is deeply involved in supporting both of her parents. "I have conversations with my dad like we used to, but I have to actively turn off the nurse in me and not just ask about his medication and newest symptoms. Just because he has PD our relationship hasn't changed," she said.

Ripley recently started a new job that gives her the flexibility to visit her parents more often. "Dad is still independent — he drives short distances, does yardwork, cooks. When I'm there, Mom can leave the house for longer stretches and focus on herself."

> **"When a parent has Parkinson's, it's important to set small family goals, things to look forward to. When I go home, I enjoy hanging out with my dad and playing pickleball with the Parkie Picklers… and getting destroyed because they are really good."**
> **- Ripley, Caregiver from Afar**

Tips for Caregiving from Afar

Ripley's family prioritizes seeing one another. "We make every family event a big deal — whether that's my sister and I coming home, my father's birthday or planning a family trip to the upcoming Disney Half Marathon, which I'll be running in as a Parkinson's Champion."


Ripley and her father at her wedding.

Ripley's advice for those caregiving from afar includes:

- Check in as often as you can, with both the primary caregiver and loved one with PD.
- Send resources. Ripley forwards Foundation emails and articles.
- Know what you can do. "I come home when I need to and when we have anything to celebrate," Ripley said.

Ripley works hard to share the load from afar. "I try to be supportive to my mom. I remind her she can't do it all. I'm always asking her to delegate something to me: call the doctor, insurance company, order groceries, dinner. Tell ME what I can do," Ripley said.

Read Ripley's full story and get inspired by more caregiver stories at Parkinson.org/MyPDStory.

Meet Two Researchers Utilizing Artificial Intelligence to Advance PD Research and Improve Care

Artificial intelligence (AI), is revolutionizing our lives in countless ways. AI often refers to computer programs that run on a process called machine learning. These programs are given a certain task and then provided large datasets from which to learn how to achieve that task. For example, an AI program designed to predict weather patterns could be "trained" on decades of meteorological data and "learn" to identify which patterns of wind, temperature and humidity could likely result in a thunderstorm. Parkinson's disease (PD) research and care is no exception to the modern AI trend. Meet two researchers using AI to improve the lives and futures of people with PD.

Meet Jeff Kim, PhD

Parkinson's Foundation 2025 Postdoctoral Fellowship Recipient

Parkinson's Foundation research has found that approximately 13% of people with Parkinson's have a genetic link to the disease. PD-associated DNA mutations affect the production and function of critical proteins, potentially contributing to disease risk or symptom progression. While many high-profile PD-associated mutations have been discovered in genes such as *LRRK2, GBA and SNCA*, Jeff Kim, PhD, is taking the field further by using artificial intelligence to:

- Understand how overlapping types of PD mutations can affect the chances of developing PD.
- Dig deeper into the genetic data to find more subtle, hidden mutations that might impact the risk for developing PD.

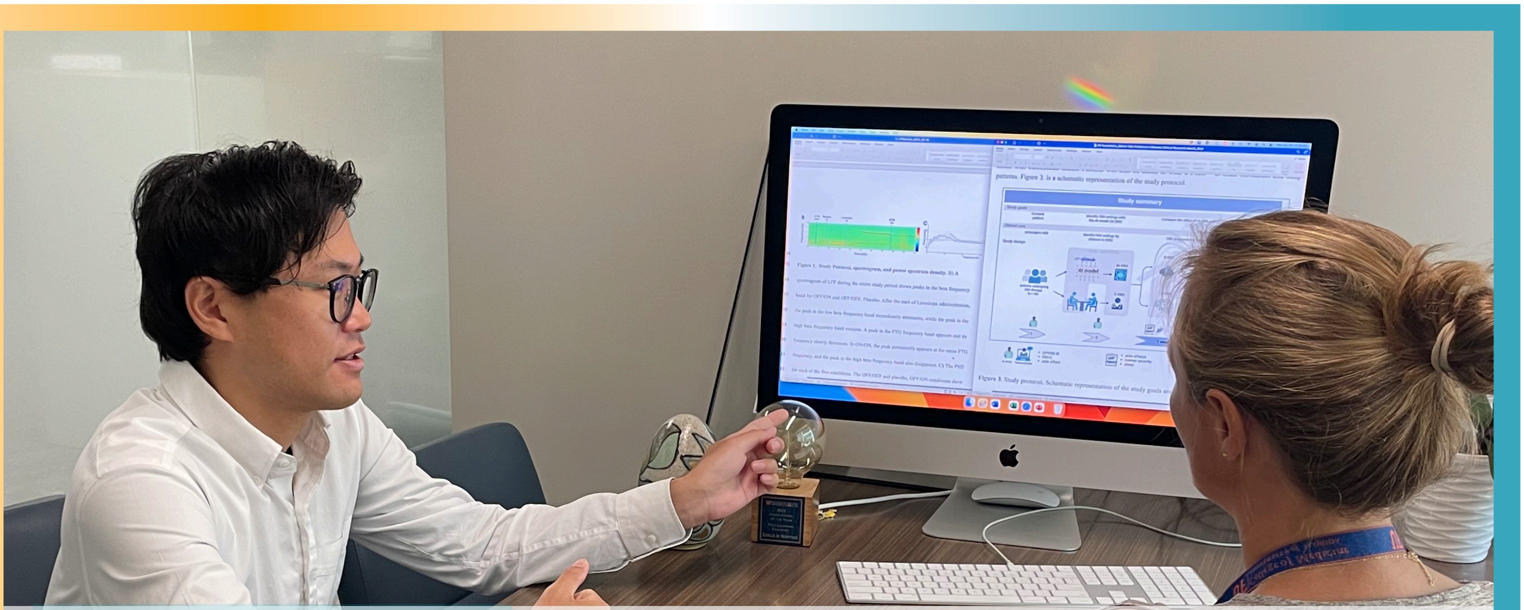
At first, genetic studies of PD were focused on finding single, rare mutations most associated with disease. As techniques improved, researchers have been able to roughly measure the risk of developing PD by adding up the risk from multiple common mutations. However, "while we know that both rare gene mutations and combinations of common genetic variations can cause PD, we rarely study how these two types of genetic risk work together or change with age," said Dr. Kim.

With his colleagues in the lab of Dr. Joshua Shulman at the Baylor College of Medicine in Houston, Texas, Dr. Kim is utilizing a new statistical tool called the "Causal Pivot Model" to better understand the complexities of PD mutation combinations. This model works on a simple principle: people with PD with rare single mutations usually don't have many common mutations. By looking at this pattern, the model can spot people who likely carry hidden rare single mutations that haven't been found yet. Dr. Kim is also building age into the model, since some mutations cause PD early in life while others strike later — this could help identify people at risk for early-onset disease.

Once the model has been tested and trained on enough data, Dr. Kim's next goal is to combine the Causal Pivot Model with an advanced AI model called AI-MARRVEL to identify hidden potential PD mutations, ones that have been overlooked in previous analyses but can be spotted by this powerful tool. These mutations can then be tested in fruit flies, observing if they result in Parkinson's-like symptoms and leading to novel therapeutics in the future.

> "Ultimately, this project aims to move us closer to clinically useful genetic information that could eventually guide personalized treatment strategies for people with Parkinson's disease."
>
> - Dr. Kim

(continued on next page)



Meet Hikaru Kamo, MD, PhD

2025 Melvin Yahr Parkinson's Disease Clinical Research Award

While medication is the most common way to help manage PD symptoms, when drugs begin to lose their effectiveness, deep brain stimulation (DBS) may be an option for some people with PD. The treatment involves implanting electrodes into the brain that deliver controlled electrical stimulation that counteracts the disruptive symptoms of the disease.

Hikaru Kamo, MD, PhD, is investigating if AI can be used to automate and optimize DBS programming. "As DBS technology advances, its complexity increases," said Dr. Kamo. "Adjusting the stimulation settings requires specialized expertise, which may not always be available. This creates a gap where patients may not receive optimal care unless they are under the supervision of a specialist."

During his time as chief medical resident at Juntendo University in Japan, Dr. Kamo treated many people with PD and other movement disorders, gaining firsthand experience with providing DBS treatment. Fascinated by this technology, he then earned his PhD by exploring the science behind DBS and how it can be improved.

In 2024, Dr. Kamo received a travel grant from the Japanese Society of Neurology to join the University of Florida and continue his work. It is there that, thanks to the support of this award, he will study how AI could be used to improve DBS treatments for people with PD.

"Preliminary results suggest that AI-generated settings align with physician-determined settings in about 90% of cases," said Dr. Kamo. "Currently, physicians adjust DBS settings based on clinical evaluation called monopolar-review, which needs more than 30 minutes of evaluation, but as the technology becomes more complex, AI-assisted programming could simplify the process."

While the AI programming and coding is complicated, Dr. Kamo's research study is straightforward. Thirty patients with PD will receive one DBS treatment using settings manually set by a physician, and then another treatment using settings generated by a specialized AI program. This study will be blinded, meaning that both the researchers and participants will not know which treatment is which (physician or AI) until after all data is collected and analyzed.

Dr. Kamo's research has the potential to improve DBS in many ways, specifically, making the treatment more effective and usable for people with PD and doctors.

> **"If successful, this research could demonstrate that AI-driven DBS programming is as effective, if not more, than traditional methods, offering a more consistent and accessible treatment option for patients. I am honored to be recognized by such a prestigious organization and am committed to conducting research that lives up to this recognition." - Dr. Kamo.**

Learn more about our ongoing research at Parkinson.org/Research.

Helping a Loved One with Advanced Parkinson's

What is considered advanced Parkinson's?

There is no single definition of "advanced" Parkinson's, as PD progresses differently for everyone. Healthcare professionals use various scales to measure progression. In general, PD is considered advanced when a person is no longer physically independent.

When Parkinson's disease (PD) progresses to an advanced stage, a person may experience substantial movement, communication and medical challenges. Here are things to watch for, along with ways to provide your loved one with the best possible care:

- PD can cause soft or slurred speech and make it difficult for your loved one to comprehend complex sentences. Try to speak slowly and simply, while minimizing outside noise and distractions.
- As mobility becomes more challenging, the risk of falls increases. Physical and occupational therapists can assess your loved one's needs and teach you how to adapt your environment and encourage safe movement.
- Swallowing problems can complicate eating and drinking. Serve nutritious, easy-to-eat foods and encourage frequent sips of liquid. A dietician can help modify your loved one's diet and minimize weight loss.
- People living with advanced PD face increased risk of aspiration pneumonia (infection from food entering the airway or lungs). If your partner is having trouble swallowing, ask to see a speech-language pathologist.
- Advanced dementia — intense thinking and memory changes — can cause a person with PD to sense things that are not real or become agitated or paranoid. Calm communication can diffuse tense situations. Rather than arguing or using reason, try to peacefully acknowledge what your loved one is experiencing.

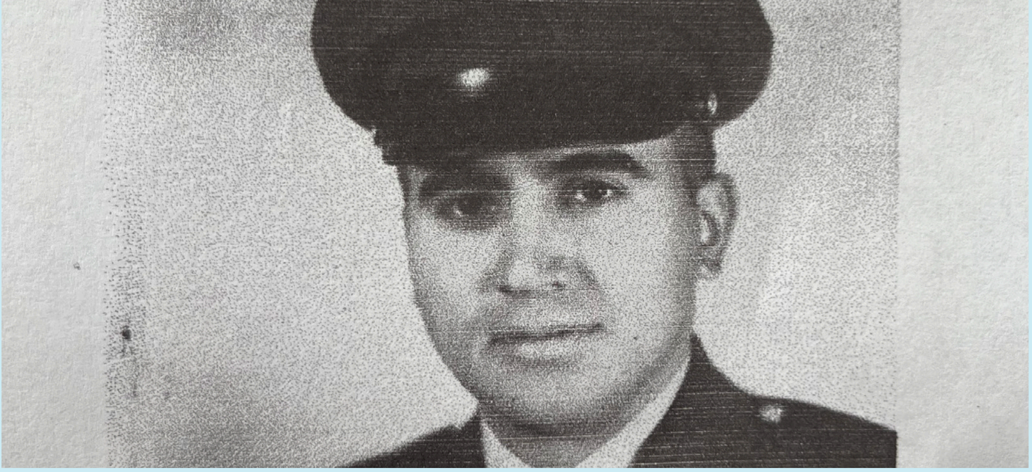
Outside Care

As Parkinson's advances, care needs also progress. If you are already receiving help from friends and family, or a day care or home health aide service, consider whether increased outside help could improve quality of life for you and your loved one. Full-time in-home care or a skilled nursing facility may gradually become necessary.

If you rely on family or other local helpers for help, be sure everyone is aware of your loved one's current needs and challenges. Check in regularly with your care team and monitor quality of care. Calmly address any concerns or problems.

A person's journey with Parkinson's can be unpredictable. Deciding when to consider hospice services is difficult. Hospice, provided at home or in a care facility, may better manage substantial health issues for those facing end of life, such as advanced dementia, recurrent pneumonia, infections or pain. When you are both ready, your partner's doctor can begin the process with a hospice referral.

Visit Parkinson.org/AdvancedPD for more information on caring for someone with advanced PD.



How Cal Ensured His Fight Against Parkinson's Continues

When Cal Renteria was diagnosed with Parkinson's disease (PD) in his 60s, he was determined to remain active to fight PD and learn as much as he could about the disease. His father also had Parkinson's disease, so he was not a stranger to it, but he wondered if it was genetic and what research was being done to better understand and fight PD, which led him to the Parkinson's Foundation.

"He always took care of himself and was active," said his sister, Emilia Eglitis. "Other than Parkinson's, he was in good health. As an engineer, he was scientifically oriented and always wondered about Parkinson's research. He would read anything he could, and we would send each other articles. He wanted to help out and contribute to Parkinson's research."

Before Cal passed away in 2024, he told Emilia he would like to update his will to include the Parkinson's Foundation.

"He didn't get around to making the updates he wanted to his will," Emilia said. "But I went to visit him and I asked: 'What is it you need? What is it that we didn't get done that you would like me to do?'"

"He said 'I want to give money to the Parkinson's Foundation.' I promised I would do that for him,"

Emilia has made several generous planned gifts in Cal's honor, ensuring his wishes were fulfilled.

"I admire his generosity," she said. "This is what he wanted. I hope it is helpful to the Parkinson's Foundation and that we get a better understanding of why people get this disease, which is what he wanted to know."

Make a lasting impact with a planned gift to the Parkinson's Foundation. Learn more at Parkinson.org/PlannedGiving.

Parkinson's Champions live around the world — including Palmer, AK! In August, Jillian Quinn hosted Alaska's Golf FORE Parkinson's Tournament. Inspired by her father's journey with PD, the event united the community to tee off against PD, raising funds and sharing Foundation resources.

Become a Parkinson's Champion at Parkinson.org/Champions.

"I started participating in Parkinson's Revolution in 2021 and I was so happy for my mom to join me on the bike this year in 2025! She understands exercise is one of the best things she can do to manage her PD and has participated in Rock Steady Boxing classes in Northern Indiana since her diagnosis."

- ***Melanie Hannon, Team Sally's Spinners, Parkinson's Revolution Chicago***

Sign up for Parkinson's Revolution at Parkinson.org/Revolution..

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