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january

8-12 DISNEY WORLD MARATHON WEEKEND

30 DISNEYLAND HALF MARATHON WEEKEND

february

2 LIFE TIME MIAMI MARATHON WEEKEND

22 PARKINSON'S REVOLUTION
Sign up at [Parkinson.org/Revolution](https://parkinson.org/Revolution)

march

12 EXPERT BRIEFING: NOURISHING WELLNESS: NUTRITION FOR PD
Register: [Parkinson.org/ExpertBriefings](https://parkinson.org/ExpertBriefings)

15 MOVING DAY THE VILLAGES, FL

15-16 LOS ANGELES MARATHON WEEKEND

17 UNITED AIRLINES NYC HALF MARATHON

29 MOVING DAY SAN ANTONIO

april **PARKINSON'S AWARENESS MONTH**

5 MOVING DAY PALM BEACH

9 EXPERT BRIEFING: THE LATEST ADVANCES IN PD RESEARCH AND TREATMENT
Register: [Parkinson.org/ExpertBriefings](https://parkinson.org/ExpertBriefings)

12 MOVING DAY LEXINGTON
MOVING DAY SOUTH ALABAMA (MOBILE)

19 MOVING DAY LAS VEGAS

26 MOVING DAY BATON ROUGE
MOVING DAY CHARLESTON
MOVING DAY KNOXVILLE
MOVING DAY VENTURA COUNTY, CA

27 BIG SUR MARATHON WEEKEND
EUGENE MARATHON WEEKEND

Helpful Parkinson's Resources

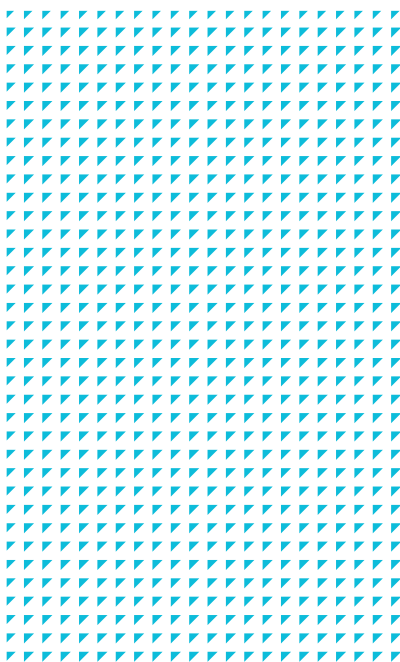
In honor of National Family Caregivers Month, we are sharing resources that can help care partners and their loved ones with Parkinson's disease (PD) live better lives:

- 1. Helpline** — Get answers to your PD questions and referrals to local healthcare professionals and wellness programs.
1-800-4PD-INFO (1-800-473-4636) or Helpline@Parkinson.org
- 2. Local Chapter** — Build connections in your community. Find your Parkinson's Foundation chapter and explore local events.
[Parkinson.org/YourArea](https://parkinson.org/YourArea)
- 3. Virtual Courses** — Visit our Learning Lab for self-paced Care Partner Program online courses featuring care partners and PD experts.
[Parkinson.org/LearningLab](https://parkinson.org/LearningLab)
- 4. PD Library** — Dive into the symptoms and topics that matter most to you.
[Parkinson.org/PDLibrary](https://parkinson.org/PDLibrary)
- 5. PD Health @ Home Events** — Register for new, weekly online events (including exercise classes you can do together).
[Parkinson.org/Events](https://parkinson.org/Events)

Explore all our Parkinson's resources at [Parkinson.org/Resources](https://parkinson.org/Resources).



VIKAS CHINNAN



Update From Our People With Parkinson's Advisory Council Chair

I was on a long, misdirected path before being diagnosed with young-onset Parkinson's disease (YOPD). Doctors tried treating my exhaustion, depression and rigidity before I heard the words Parkinson's. Although I was open with my family when my symptoms began, it took years before we learned how to fight this disease, together.

Over time, I learned how to fight the hidden non-movement symptoms of PD that took us by surprise. Educating myself, finding exercise classes and therapy helped me regain some control — and ultimately led me to the Parkinson's Foundation, where I set out to help people living with PD and their care partners fight these symptoms.

I'm excited to serve as the People with Parkinson's Advisory Council Chair. Not only do I get to work alongside people with Parkinson's and care partners, but I get to bring awareness to the invisible symptoms that come with this disease.

As a husband and dad of two boys, this issue not only aims to empower readers but helps shed light on how PD impacts the entire family. Information is key to helping care partners avoid burnout (see page 4), explore tips for parenting with PD (page 8) and ways to help your parent with PD (page 6). These articles reflect the many ways PD impacts the one million people living with Parkinson's in the U.S. and their families.

This November is National Family Caregivers Month. We dedicate this issue to care partners — to those who know the visible and invisible symptoms of PD too well. Help us make an impact at Parkinson.org/CaregiversMonth.

VIKAS CHINNAN

People with Parkinson's Advisory Council Chair

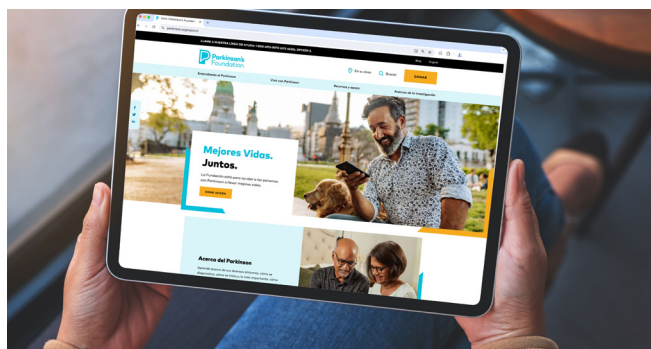
Self-Paced Care Partner Courses

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

Parkinson.org/LearningLab



Explore Our Resources in Spanish



Articles and tools created for the Spanish-speaking PD community.

Parkinson.org/Espanol.

8 Tips for Avoiding Caregiver Burnout



November is National Family Caregivers Month. This year, the Parkinson's Foundation is highlighting the importance of caregiver well-being by acknowledging the challenges of caregiver burnout. Addressing caregiver burnout is essential, as it can affect the caregiver's health and their loved one living with Parkinson's disease (PD).

Just as Parkinson's and its symptoms evolve over time, so does the role of a care partner. If you're experiencing signs of caregiver burnout or trying to prevent it, here are eight tips that can help:

Tip 1:

Make Time for Yourself

Actively carve out moments for self-care and relaxation. Taking breaks allows you to recharge mentally and emotionally, reducing the risk of burnout. Balance is key — neglecting your own needs can lead to exhaustion. Whether it's a daily walk, reading a book or pursuing a hobby, moments of respite are crucial for sustaining your ability to provide long-term support.



What is caregiver burnout?

Caregiver burnout is a state of physical, emotional and mental exhaustion that may include a change in attitude, from positive and caring to negative and unconcerned.

Signs can include:

- Fatigue
- Irritability, frustration or anger
- Feelings of hopelessness or helplessness
- Changes in sleep patterns
- Withdrawal from social activities

Tip 2:

Set Realistic Expectations

Be realistic about what you can handle. Prioritize tasks and focus on what's most important. Understand your capabilities and limitations and ask for help when you need it.

Tip 4:

Delegate & Accept Help

Learn to ask for outside help, especially if you are the primary care partner. Whether family, neighbors, friends or professionals, you don't have to do everything on your own. Asking a family member to watch TV with your loved one can score you time to see a movie or go to a support group meeting.

Tip 7:

Exercise Regularly & Get Enough Sleep

Regular exercise has been linked to lower depression and stress levels, and better sleep. Find something you enjoy — a nature walk, yoga or a workout class. Aim for seven to nine hours of sleep at night to maintain physical and emotional health.

Tip 5:

Seek Emotional Support

If you're unsure how to navigate an aspect of caregiving, seek advice from a healthcare professional, support group or experienced caregivers. They can provide valuable insights and tips based on experience. Connecting with others who understand your situation can help reduce feelings of isolation and self-doubt. Therapy is also a safe space to express yourself, find new perspectives and develop coping strategies.

Tip 8:

Incorporate Stress-Relief Techniques

Finding ways to relieve stress as part of your routine can improve your ability to manage burnout. Techniques like deep breathing exercises help calm the mind and reduce physical tension. Meditation offers a chance to practice mindfulness, allowing you to step back from stressors and regain perspective.

"Having conversations with my partner and my friends about what is required of me as a caregiver has been important. Sometimes I just need more flexibility with plans because things can change quickly with my mom's care."

**CARLA VELASTEGUI,
CAREGIVER**

Read Carla's story on page 7



Tip 3:

Celebrate Small Victories

Recognize the progress you've made in your caregiving journey. These milestones, whether big or small, serve as reminders of your dedication and the positive impact of your efforts on your loved one's well-being.

Tip 6:

Getting Organized

Organizing can help you avoid feeling overwhelmed — finding a system to help keep track of appointments, medications and important documents can help. As a caregiver, some things are out of your control. Try to stay flexible because as you know, some days (or hours) are better than others, especially when it comes to PD symptoms.

Why Addressing Caregiving Burnout is Important

Caregiver burnout can affect anyone helping a loved one. Addressing caregiver burnout helps preserve the caregiver's well-being and a supportive caregiving environment overall. You cannot pour from an empty cup. It's important to give yourself time to rest and fill up. As a care partner, your well-being is foundational to sustaining compassionate care and providing support to your loved one.

We're here for care partners. For more information visit Parkinson.org/CarePartners.



Helping A Parent Live with Parkinson's

Watching a parent navigate Parkinson's disease (PD) brings forth a flood of questions about the future. Supporting a parent with Parkinson's involves a combination of practical assistance, emotional support and education.

As a partner in care, learning about PD will help you anticipate needs and challenges. Consider attending and managing their appointments to help optimize care. Help them maintain quality of life and independence by helping them build their care team.

How will Parkinson's affect me?

Start thinking of new ways to stay connected and activities you can do together. Things will change over time as Parkinson's progresses — symptoms will evolve, while finances and responsibilities will change. Talk to your parents about your concerns. Together you can figure out solutions.

You may have to do tasks you did not have to do before. You may also have to help your parents with daily activities, like getting dressed or cooking meals. You may feel you have to do these chores, but you do not have to like it. It is okay to be angry, sad, resentful, frustrated, embarrassed or feel guilty.

Work to maintain a positive outlook.

Mindfulness exercises may help you regain focus on the present, and gratitude practices may help you savor life's small joys. Take breaks by making time for favorite activities and uplifting relationships. Seek out professional support to help you cope with the unknown, especially if anxiety is affecting your life.

Tend to feelings of grief and loss.

You may already be navigating ambiguous loss, a common experience for people with PD and their loved ones when there is a loss of emotional connection. Because of the love you have for your parent you may experience loss with every stage of PD — these losses can affect your body, mind and spirit. Trying to make healthy choices or keep a positive outlook can be difficult when you are grieving. You are tasked with being hopeful amidst painful feelings. This calls for extra attention to your self-care and maintaining connection with a caring community.

Create your well-lived life.

Focus on what you can do now to feel confident you are living your life to the fullest, despite the unknown. Ask yourself, "What would a well-lived life look like to

me?" Try to identify what brings you joy and strive to make more time for it. Seek new experiences what will help you feel whole.

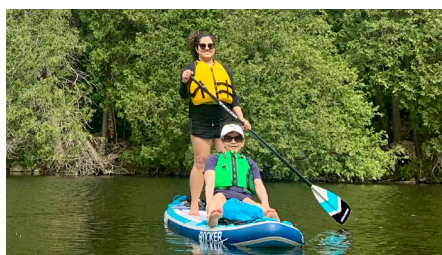
What can I do right now?

- **Schedule family chats.** Bring up issues or questions to help you and your parents understand each other and identify ways to help each other.
- **Talk to someone.** Share your thoughts with a friend, relative, counselor or support group. Expressing your concerns may help you feel better.
- **Get involved.** Sometimes we feel better when we can do something to improve a situation. Go to a local Moving Day event or volunteer with the Parkinson's Foundation.
- **Try new activities to manage stress.** Exercise and work to stay involved in your favorite activities and hobbies.
- **Get more information.** Whatever stage of Parkinson's you're navigating, we can help. Visit [Parkinson.org](https://parkinson.org) or call our Helpline at 1-800-4PD-INFO (473-4636).

Explore free, self-paced care partner courses at [Parkinson.org/LearningLab](https://parkinson.org/LearningLab).

How Carla Balances Caregiving and Building Her Life

Since she was 15 years old, Carla Velastegui has been a primary care partner for her mom, Gina, who was diagnosed with young-onset Parkinson's disease (YOPD) in her mid-40s.



Carla enjoying her hobby of paddleboarding with her mother, Gina.

"Caregiving is very much at the core of who I am," Carla said. "Helping my mom manage her Parkinson's has been a constant throughout much of my life. When I was younger, people were always shocked that I was taking on caregiver responsibilities. That's why I'm passionate about raising awareness and addressing the complex challenges caregivers face in their communities, workplaces, and healthcare systems while caring for their loved ones."

As her dad took on the role as the sole provider for the family, Carla accompanied her mom to doctor appointments. She translates for her mom, who primarily speaks Spanish, ensuring she understood and engaged with her care plan. Doctors frequently questioned her involvement in her mom's care,

which has made Carla passionate about advocating for caregivers, especially young caregivers.

"It's extremely important that young caregivers are acknowledged, supported and valued by providers, especially for immigrant communities that don't speak English," she said. "We need to ensure quality and continuity of care, especially when caring for someone with a chronic disease like Parkinson's."

Today Carla splits caregiving with her dad, who was able to retire early. But throughout her adult life, she has balanced her mom's care with building her own career and life. She's transparent with her employer, partner and friends about her responsibilities and dedicates time for herself to avoid burnout.



Carla celebrating her wedding day with her family. From left to right: Carla's sister Michelle, husband Sean, Carla, mother Gina and father Roberto.

Advocating for caregivers is a driving force for Carla. She is involved with Toronto Western Hospital, a Parkinson's

Foundation Center of Excellence where her mom receives care, and serves as a member of the Parkinson's Foundation People with Parkinson's Advisory Council, where she is one of two adult children of a person with PD.

"Realizing that my wellbeing is just as important has been an important lesson. Making time for therapy and hobbies like hiking and paddleboarding where I can just disconnect have been so helpful. I remind myself that if I'm not well, mentally, emotionally and physically, then I'm not able to take good care of my mom."

- Carla

Carla knows that with Parkinson's, every week is different and some days bring ebbing symptoms. "It can be hard to balance everything, especially while managing a full-time job and working toward personal dreams and milestones. A dream of mine is to one day have workplaces and healthcare settings recognize caregiving the way they are more prevalently recognizing parental leave. Until then, I'll keep advocating and doing everything I can to raise awareness and make that vision a reality," Carla said.

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



Practical Advice for Parenting with Parkinson's

Raising a family while living with Parkinson's disease (PD) or supporting a spouse who does, creates unique challenges. Building a stable, emotionally supportive environment can help you focus on parenting while helping your children thrive. These tips can help.



Build Trust

A child can detect when something has changed within the family. Ongoing, honest communication builds trust. When you're ready, talking openly about Parkinson's — use clear age-appropriate language to minimize fears of the unknown. Talking sooner can ease worry and help the family start to adjust.



Focus on Resilience

Discuss how Parkinson's might change day-to-day living. Navigating PD together can teach self-sufficiency and empathy. It can also help children learn healthy ways to cope with unpredictability. Share how you are taking charge of what you can — through healthy habits, exercise or finding support. Daily responsibilities can empower children and give them a sense of control. Consider volunteering as a family to give them a sense of pride. Find events you can attend as a family, such as your local Moving Day, A Walk for Parkinson's.



Create Stability

A sense of stability creates a foundation for future emotional, social and physical well-being. While some days, PD symptoms and appointments may interfere with family plans, try to maintain the style of parenting you practiced before diagnosis. Continuing the same values, rules, expectations and boundaries creates consistency. A daily, but flexible, routine benefits the whole family.



Maintain the Magic

While Parkinson's will bring change, encourage your child to pursue new experiences, interests and hobbies. Continue to be involved and support your child in what interests them.



Enlist Emotional Support

A PD diagnosis can bring a range of tough feelings for everyone — including social isolation, anger, depression, anxiety and grief. If you notice emotional changes that last more than a few weeks, connect your child with someone they can talk to. Your family doctor can refer a counselor. Also consider sharing your diagnosis with educational staff who can offer your child support during the school day.



Practice Self-Care

To meet the needs of your family, make time for your physical and emotional health. Stay on top of neurologist appointments, build your care team, exercise and eat healthy. Model healthy coping strategies by sharing your feelings, connecting with friends and finding a support group.



Keep Talking

Parkinson's is progressive. Future concerns may look different from today's challenges — and that's okay. Keep the PD conversation going. Check in regularly and celebrate the wins, both small and large.

For more resources about parenting with Parkinson's, visit Parkinson.org/ParentingwithPD.



Meet Two Researchers Working to Prevent Parkinson's and Treat Freezing Episodes

Parkinson's disease (PD) research is exciting because any scientist can discover the next breakthrough towards a cure. This year, the Parkinson's Foundation funded nearly \$3 million across 33 research grants. Meet two researchers propelling us towards a future without PD.

Meet Rebecca Wallings, PhD Parkinson's Foundation 2024 Launch Award Recipient

Immune cells play a critical role in protecting our bodies from infection and disease. As we age these cells become less effective. Rebecca Wallings, PhD, is investigating how aging impairs a specific type of peripheral (outside of the brain) immune cells and how this impairment contributes to the development of PD.

Immune cells can be divided into two groups that communicate and collaborate to help the body recover quickly and stay healthy:

- Innate immune cells are the first responders to injuries and exposures.
- Adaptive immune cells "learn" from past infections to provide enhanced protection from repeat threats in the future.

Dr. Wallings, at the University of Florida, has previously found that a PD-related mutation causes innate immune cells in older-aged brains to become "exhausted," unable to respond to infections or other inflammatory alarms in the body. Since immune cells help keep the brain healthy, this aging-related exhaustion likely has hidden causes and consequences worth exploring.

Through her Parkinson's Foundation grant, Dr. Wallings will use human cell samples from donors with and without PD to see if innate immune cell exhaustion prevents them from being able to communicate with healthy adaptive immune cells. Her research will work to better understand how this immune cell exhaustion plays into the progressive neurodegeneration common to PD.

There is evidence that this immune cell exhaustion is due to

malfunctioning mitochondria (the powerhouse of the cell). Delving into this further, Dr. Wallings will also test if reinforcing or repairing these immune cell mitochondria could have potential as a future preventative treatment option for PD.



"My research is at the forefront of a potential paradigm shift in the neurodegeneration field and may change the way researchers think about the role of the immune system in PD. What the Parkinson's Foundation has done with this award is show me that they believe in my abilities and the potential impact my research may have on the field and, most importantly, on patients' lives."

- Dr. Wallings

(continued on next page)



Meet Amitabh Bhattacharya, PhD

Parkinson's Foundation 2024 Postdoctoral Fellowship Recipient

Freezing of gait is the temporary, involuntary inability to move and is one of the more dangerous symptoms of Parkinson's because it can lead to falls. Common PD medications do not seem to help with freezing episodes, which have led researchers like Amitabh Bhattacharya, PhD, from the University of Toronto, Canada, to investigate alternative treatments. His method of choice: transcranial ultrasound stimulation (TUS).

Dr. Bhattacharya is using his Parkinson's Foundation grant to study how TUS can create personalized, non-invasive

treatments for PD patients with freezing of gait. "We will apply focused sound waves to a specific part of the brain known as the pedunculo pontine nucleus (PPN), a key region that helps control movement. By precisely stimulating the PPN, we hope to make walking easier for people with Parkinson's," said Dr. Bhattacharya.

Participants in the study will first undergo a high-resolution brain scan to create a detailed map of their brain, focusing on the PPN. This personalized brain map will guide the ultrasound device to ensure that the sound waves are

precisely directed to the right spot. Each participant will receive three personalized TUS treatments, using different stimulation protocols to determine the most effective approach. To evaluate how well each protocol works, participants will be assessed before and after each session using tests that measure their walking ability, mental function and brain activity.

"The goal of this study is to explore TUS as a practical and effective treatment for freezing of gait in Parkinson's. TUS is a non-invasive approach that could offer a quicker, more accessible, and cost-effective option. By avoiding the complexities and recovery time associated with surgical procedures like deep-brain stimulation (DBS), TUS has the potential to enhance mobility and improve quality of life. If successful, this study could position TUS as a valuable tool in the treatment of Parkinson's and other movement disorders."

- Dr. Bhattacharya

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

4 Ways to Engage in Parkinson's Research

Parkinson's research is the only way we can improve and develop treatments, and one day a cure. Here are four ways you can engage in research:

1

Enroll in PD GENERation:

This study offers genetic testing and counseling at no cost for people with Parkinson's. Parkinson.org/PDGENERation

2

Explore ongoing PD studies and opportunities to get involved with PD research at Parkinson.org/JoinAStudy

3

Become a research advocate: This program brings together people who live with PD and those developing new treatments. Parkinson.org/ResearchAdvocate

4

Read Science News: We sort through the latest published PD research studies and give you the takeaways. Parkinson.org/Blog



Neilia's Commitment to Find A Cure In Honor of Her Sister

Neilia LaValle first learned about Parkinson's disease (PD) when her sister, Cecelia, was diagnosed in the early '90s after noticing rigidity in one of her arms. After the diagnosis, Neilia and the family rallied around Cecelia, researching PD and supporting her as she explored treatment options.

"We are a close family," Neilia said. "The impact Parkinson's had on my sister and the whole family was tremendous. She was an integral figure in our family and had so much enthusiasm for life. She was an entrepreneur, a great artist and a wonderful cook who loved to bring the family together. She fought hard, but Parkinson's took so much from her."

Before Cecelia passed away in 2016, Neilia spoke to a friend who had recently started her own non-profit to raise money for breast cancer, which inspired Neilia to do the same and support a cause near to her heart — Parkinson's disease.

"Seeing what my sister was going through made me want to help find a cure for Parkinson's," Neilia said. "Watching a loved one deteriorate is terrible and I don't want other people to go through what my family and my sister went through."

Now, Neilia uses her foundation to support organizations like the Parkinson's Foundation that are working to find a cure for PD. She's proud to honor her sister and to continue her fight for a cure.

"It seems like more and more people are directly impacted by Parkinson's," she said. "We need to get more people actively involved in supporting organizations that are looking for a cure. There is hope, and that is what we need to use to keep us going."

With your support, we can invest in research that will help us find new treatments and a cure for Parkinson's in years, not decades. To make a donation, visit Parkinson.org/Donate.



Bill Kelley ran the 2024 Boston Marathon as a Parkinson's Champion, raising more than \$10,000. Bill has completed all six Abbott World Major Marathons, pushing himself to help make life better for people living with Parkinson's in memory of his mother Wilma.

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



Deb Pollack, founder of non-profit Drive Toward a Cure® aligns with car clubs and organizations nationwide raising funds to benefit Centers of Excellence and funding grants. Atlanta's Peachstate Porsche Club contributed \$30,000 for the Parkinson's Foundation Center of Excellence at the Jean and Paul Amos Parkinson's and Movement Disorders Clinic at Emory University through a combination of one-day drives, poker runs and museum and garage tour programs.

Explore ways to give at Parkinson.org/Donate.

LEAVE A MEANINGFUL LEGACY THROUGH YOUR ESTATE

Join the Parkinson's Foundation Legacy Society when you designate us as a beneficiary in your estate plans. You can make a difference in people's lives and create a meaningful legacy. Simply designate a percentage of your estate via your will or trust.

Learn more at Parkinson.org/PlannedGiving or email us at Legacy@parkinson.org.

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