Calendar of Events

Update From Tom Manak, People with Parkinson's Council Chair

New Online Courses for the Parkinson's Community

Announcing the Reach Further Campaign to Accelerate Research

FEATURE
Self-Care for Care Partners: How to Incorporate Mindful Resilience

Essential Care Partner Resources

Valuable Care Partner Life Lessons

Charting a Course for Parkinson’s Care

Care Partner Grief: 8 Ways to Care for Yourself During Bereavement

Board Members Help Us Get Closer to a Cure
Events

Virtual events are open to all and available online. View all upcoming events at Parkinson.org/Events.

FEBRUARY

2 Expert Briefings Webinar: Sights, Sounds and Parkinson’s
   Register: Parkinson.org/ExpertBriefings

MARCH

2 Expert Briefings Webinar: Conversations about Complementary Therapies and PD
   Register: Parkinson.org/ExpertBriefings

ALWAYS AVAILABLE

PD Health @ Home educational and wellness events are designed for YOU. Check out our exciting new themes and webinars at Parkinson.org/PDHealth.

APRIL

2 Moving Day Westchester County, NY
   Sign up: MovingDayWestchesterNY.org

6 Expert Briefings Webinar: Can We Put the Brakes on PD Progression?
   Register: Parkinson.org/ExpertBriefings

9 Moving Day Charleston
   Sign up: MovingDayCharleston.org

16 Moving Day Ventura County
   Sign up: MovingDayVenturaCounty.org

23 Moving Day San Antonio
   Sign up: MovingDaySanAntonio.org

30 Moving Day Las Vegas
   Sign up: MovingDayLasVegas.org

People with Parkinson’s Disease and parkinsonism have a higher risk of fractures

The TOPAZ study will test if a medicine called zoledronate can prevent fractures and decrease the risk of death in those:
- aged 60 years or older
- with Parkinson’s Disease or parkinsonism

If you are eligible for the study, a nurse will come to your home and you’ll receive a one-time treatment (either zoledronate or placebo).

Want to join or learn more about TOPAZ?
Call: 1-800-4PD INFO
(1-800-473-4636)

Join the Parkinson’s Foundation Surveys initiative to make sure your voice is heard!

Sign up at Parkinson.org/Surveys.
Update from Tom Manak, Our People with Parkinson’s Council Chair

This November is National Family Caregivers Month, and it is a particularly special one for me. My wife, Ro, lived with Parkinson’s disease (PD) for 31 years. Together, we learned how to navigate this disease and build a community of support and love.

This issue is dedicated to care partners. It is for those of you who just went to your first support group or your first care partner support group, to those who never miss a group exercise class alongside your partner, to those who make difficult decisions and balance everyday activities while never missing a medication alarm.

As the first care partner to lead the People with Parkinson’s Council, it is my honor to help provide the Foundation with the perspective of people living with Parkinson’s and their care partners. We are constantly working to empower the Parkinson’s community and provide new and timely resources, like this newsletter.

From personal experience, I know caring for a loved one with Parkinson’s can be really hard and at times you can easily forget to prioritize yourself. Join us this November for our Be a SelfCareGiver campaign. All month long we will highlight ways care partners can focus on self-care, and hopefully, help you integrate these concepts throughout the year.

Helpful Ways to #BeaSELFCAREgiver

As a care partner it is important to be intentional with your own physical and mental health, which is why this National Family Caregivers Month, the Parkinson’s Foundation and Kyowa Kirin are joining together to help you prioritize your well-being. Here are four ways you can #BeaSELFCAREgiver:

1. Engage in mindfulness exercises.
   Setting aside a few minutes each day to meditate can greatly improve your mental health. Get started with guided relaxation at Parkinson.org/MindfulnessMondays.

2. Take a care partner course.
   Our self-paced online courses cover topics like caregiver burnout and self-care strategies, with worksheets and tips. Visit Parkinson.org/CarePartnerProgram to register.

3. Start a conversation.
   Communicating your own thoughts and feelings as a care partner is essential. Download our Care To Talk cards for conversation starters at Parkinson.org/CareToTalk.

4. Join a support group.
   Share your experiences and interact with fellow care partners in an understanding environment. Join our online community at Parkinson.org/PDConversations.

Join us as we highlight ways you can #BeaSELFCAREgiver at Parkinson.org/CaregiversMonth.
New Online Courses for the Parkinson’s Community

From ordering groceries and attending telehealth appointments, to streaming exercise classes, online services have optimized daily life — without ever needing to leave the house. The Parkinson’s Foundation is launching new, online resources to help make life better for people with Parkinson’s disease (PD) and those who care for them.

“The Parkinson’s Foundation is working to improve and tailor our online educational courses to empower everyone who is a part of our community — from people living with Parkinson’s to care partners and members on the healthcare team,” said Eli Pollard, Parkinson’s Foundation Vice President and Chief Training and Education Officer. “We wholeheartedly believe this new wave of resources will allow people with Parkinson’s to be their best advocate.”

For Care Partners
Launched this year, “The Care Partner Program: Building a Care Partnership” is a one-of-a-kind program that offers self-paced online courses. Every course features videos, writing prompts and opportunities to connect with care partners around the world about the topics that are most important to you.

Through this program, care partners will be able to utilize tools to help aid them in managing their loved one’s care, create actionable strategies for self-care, develop clear networks for support and access relevant tools that will support them in their role as care partner. Sign up at Parkinson.org/CarePartnerProgram.

For Healthcare Professionals
The Parkinson’s Foundation will soon offer a Certificate for completion or Continuing Medical Education (CME) credit for healthcare professionals. To improve care for people with Parkinson's, the Foundation focuses on best-practice care training through professional educational courses. In its first accredited course, the Foundation will guide healthcare professionals through Parkinson’s and genetics. These courses will be open to all in the PD community. Sign up at Parkinson.org/ProfessionalEducation.

For All in the PD Community
The all-new Cognition Talk Series is a seven-part online course that focuses on cognition concerns and challenges of living with Parkinson’s. A specialized health professional guides each 30-minute section providing expert insight for CME or certificate. Sign up at Parkinson.org/OnlineCourses.

PD Health @ Home offers fresh weekly educational and wellness online events. Mindfulness Mondays start the week with guided videos that help reduce stress. Wellness Wednesdays explore a newsworthy PD topic guided by an expert. Fitness Fridays allow attendees to get moving with PD-tailored fitness videos. Sign up at Parkinson.org/PDHealth.

Register for upcoming Parkinson’s Foundation virtual events at Parkinson.org/Events.
A new Parkinson’s Foundation fundraising campaign aims to increase access to quality of life for all people with Parkinson’s disease (PD). Launched in September, Reach Further is a four-year fundraising campaign that will invest an additional $30 million to expand the Foundation’s reach, while advancing research toward a cure.

The Parkinson’s Foundation is ready to embark on a greater, bolder push for health equity. The Reach Further campaign will evolve our mission, moving the Foundation on the offensive to boost our streamlined research initiatives, bring effective programs to more communities and designate new centers that specialize in Parkinson’s care.

Kayln Henkel, Parkinson’s Foundation Senior Vice President and Chief Development Officer

Reach Further uniquely positions the Parkinson’s Foundation to address the current and future demands of the PD community. “When we raise these funds, we will increase access to care for local communities,” said Josh Raskin, Reach Further national co-chair and Parkinson’s Foundation board member. “This campaign will allow us to help a much bigger percentage of people with Parkinson’s and keep us on the path to research breakthroughs.”

The Reach Further campaign will provide much-needed funding in support of three bold initiatives:

1. **Advancing Research**
   High-quality research will lead to new PD medicines, better therapies and eventually a cure. From frontline doctors and geneticists to scientists running clinical trials, a broad continuum of investigation is critical to advancing the science on Parkinson’s. Through this campaign, intensifying PD research efforts will allow the Foundation to improve the lives of those living with Parkinson’s today, as well as the future for those not yet diagnosed.

   Reach Further funding will help the *PD GENERation: Mapping the Future of Parkinson’s Disease* research study provide genetic testing and counseling for up to 15,000 people with Parkinson’s at no cost to them.

2. **Expanding Our Clinical Care Network**
   Comprehensive Parkinson’s resources and treatment in the U.S. is not easily accessible outside of the Parkinson’s Foundation Centers of Excellence network. This campaign will fund better, more attainable care to the one million Americans living with Parkinson’s, raising $5 million to broaden our clinical care network to areas in need of comprehensive PD care.

3. **Growing Community Programs**
   Parkinson’s Foundation community education programs and grants bring resources to people living with Parkinson’s and their families. The Reach Further campaign will provide $5 million to increase support of community programs to educate and empower while providing information on mental health, care partner support, newly diagnosed services and more for people with Parkinson’s and their families.

Help Us Reach Further. Donate today at Parkinson.org/Reach.
Think of a positive word that is meaningful to you. Some may think of a word quickly, while it may take longer for others.

“The most resilient of us acknowledge the difficult and we consciously choose to pivot toward the positive,” said Maria Sirois, PsyD, during her Parkinson’s Foundation “Mindful Resilience for Care Partners” webinar. “What does that mean in the context of someone caring for a loved one with Parkinson’s? It means that every day presents its stressors and challenges, but every day also presents an opportunity to integrate the positive. Why is this important? Research shows that we do better when we spend time in positive states, like being happy or feeling appreciated.”

Mindful resilience utilizes the practice of mindfulness to improve your ability to manage stress, calmly make decisions and increase optimism. Dr. Sirois highlights five tips for incorporating mindful resilience into your everyday life:

**Shape Your Day**
Beginning your day with a routine can help you feel in control of your mind and body. Every morning ask yourself, “What can I do today that might strengthen me, calm me or inspire me?” Whether that is exercising,
painting or taking a bath, spend 10 to 15 minutes each day doing something you enjoy. Learning to practice self-care daily, if only for a few minutes, will reenergize you throughout the week.

Try Mindful Pausing
Set aside three to five minutes per day to engage in a mindful pausing exercise. Close your eyes, take deep breaths and focus on your breathing. If your mind begins to wander, acknowledge the distraction for a moment, then quickly return to focusing on your breath.

Mindful pausing and similar meditation exercises offer many benefits, including calmer decision making, less agitation and better sleep quality. “Some of the most important benefits have to do with the physiological calming of the nervous system along with psychological calming,” said Dr. Sirois. “We start to feel like we’re a little bit more relaxed, a little bit more at ease and a little bit more in control.”

Learn to Say No
In addition to advocating for your loved one, learning to advocate for yourself is essential. Though it may seem difficult at first, learn to say no to things that drain you or overwhelm you “Saying ‘no’ a little more frees us up to say ‘yes’ to the things that give us joy,” said Dr. Sirois. Prioritizing self-care and practicing mindfulness will ultimately make it easier to say no to unpleasant or unwanted feelings and increase your overall happiness.

Acknowledge the Difficult
Being a care partner can be challenging. Some days, this role may feel overwhelming. Part of mindful resilience includes recognizing the struggles you are experiencing and finding healthy ways to cope with them. “The most resilient of us acknowledge the difficult. We face it, we do our best to manage it and we consciously, mindfully choose to pivot toward the positive whenever possible,” said Dr. Sirois.

Remember That You Matter
It can be easy to neglect your own well-being while you are balancing caregiving, as well as your personal and professional life. Practicing self-care is the number one way to prevent burnout, which proves that taking time for yourself is not only beneficial to you, but to the person in your care, as well. When life gets particularly stressful or difficult, remember this advice from Dr. Sirois, “What we’re looking to do is build better moments.” Engaging in mindful resilience is one way to build better moments for yourself and those around you.

With all the unexpected challenges of the past year, the 2021 Parkinson’s Foundation Care Partner Summit | Cumbre Para Cuidadores addressed mental health for care partners. Dr. Sirois’ two-part series on mindful resilience was one of the most popular virtual webinars of the summit (watch the summit at Parkinson.org/Summit).

For more articles created for care partners, visit Parkinson.org/Caregivers.

Essential Care Partner Resources
We support and empower everyone caring for a loved one with Parkinson’s disease (PD) with tools and information to make day-to-day activities easier:

1. Caring and Coping. This free guide provides caregiving tips, stories and tools. Parkinson.org/Library

2. Care Partner Program. Self-paced courses, complete with guides and tip sheets. Parkinson.org/CarePartnerProgram

3. Parkinson.org. Dedicated articles to help you navigate all stages of PD. Parkinson.org/Caregivers

4. Helpline. Get answers to your PD questions and referrals to resources. 1-800-4PD-INFO (473-4636)

5. YouTube Playlist. Watch our YouTube care partner playlist. Youtube.com/Parkinsondotorg

6. Support Group Guide. This updated guide will help you start your ideal group. Parkinson.org/Library

7. Resource List. Utilize this list of organizations that offer resources and services for care partners. Parkinson.org/CaregiverResources
For Dean and Bill, the collapsing bridge was Parkinson’s disease (PD). After years of doctors finding “nothing wrong” with Bill, his stomach pain and shuffling gait eventually turned into dangerous falls. Eventually, Bill saw a movement disorder specialist.

“We were reeling from that diagnosis,” Dean said. “We took care of ourselves. We were two gay men from metro New York who survived the Con Edison blackouts, stock market crash, 9/11, the AIDS crisis, and yet, Parkinson’s wasn’t something we could solve.”

They quickly found themselves with no answers, until they discovered the Muhammad Ali Parkinson Center at Barrow Neurological Institute in Phoenix, AZ, a Parkinson’s Foundation Center of Excellence (a medical center that specializes in the latest PD care and treatment). “I thank instructors, support groups and the Barrow team who opened doors we could never have imagined.”

It took time for the couple to re-learn that they were still a team.

“I’d try to jump in and fix everything because he was sick. He was sick — not dead,” Dean said. So, we worked together, to be collaborative.”

As a care partner, Dean began experiencing depression. At his support group he learned he was not alone. “I found a wonderful therapist and was prescribed an antidepressant. I cannot tell you what a difference that has made.”

When it comes to relationship maintenance, Dean and Bill follow “The Table” approach, where they set a monthly appointment with one another. “It’s a space to try to construct a better relationship and plan for the future. It’s been a journey of 17 years together now. I say to him, ‘I love you more every day.’”

While Parkinson’s has modified Bill’s radio-quality voice, several years ago, his speech therapist invited Bill to perform at a local PD choir’s Christmas performance. Each “Troon Tunes” singer was then asked to share their most memorable Christmas. Bill said, “Being with my life partner Dean makes every day feel like Christmas.”

Anyone dealing with Parkinson’s knows change is constant. The couple recently moved to a new apartment for its better safety and traded their small hybrid for a van with accessibility features. “We made these changes because I don’t want Bill to feel isolated, to feel that he’ll never get out of the apartment because it’s not easy.”

Being a care partner has taught Dean many life lessons. “Look at the situation logically, get information. Then, decide to push the limit or stay within your comfort zone.” In addition to keeping health appointments and avoiding isolation, he wants to remind care partners that “everyone has at least one burden they struggle with. I’m just a human being saying: ‘Someone is rooting for you. Something is going to happen for you.’”

While Parkinson’s symptoms, apartments and mantras may change, the love Dean has for his life partner and his optimism remains steadfast. “In closing, I would like to say that care partners are loving, giving, caring people, both beautiful in spirit and strong in heart,” Dean said.

Share your PD Story at Parkinson.org/MyPDStory.
Finding a Baseline
Taking a symptom snapshot and regularly assessing your PD progression can ensure that you and your doctor consider appropriate care for every stage. This can also help you plan for challenges before they happen.

Doctors skilled in Parkinson’s often use symptom assessments, along with evaluations such as the Unified Parkinson’s Disease Rating Scale (UPDRS) — exploring mood changes, motor (movement) symptoms and impacts on daily living — to get a picture of your PD progression. Such evaluations also monitor non-motor symptoms, common in Parkinson’s, including everything from sleep to speech problems.

Exploring Parkinson’s Stages
The Hoehn and Yahr PD scale classifies Parkinson’s into five general stages. This scale is mostly used for research, but can also help explain how PD impacts quality of life:

- **Stage One:** Mild motor symptoms, such as tremor, initially affects one side of the body. This early stage and the next can potentially last for up to 10 years.
- **Stage Two:** Motor symptoms, including stiffening, begin to become noticeable on both sides of the body.
- **Stage Three:** At this mid-stage, trouble with balance increases fall risks. Physical and occupational therapy, along with walking aids can help.
- **Stage Four:** As symptoms progress — usually for those with PD for 18 years or more — the need for assistance with tasks, caregiving and risk of falls increases. Around 80% of people who have lived with Parkinson’s for 15 years will have recurrent falls.
- **Stage Five:** Tasks are difficult at this advanced PD stage. Comprehensive caregiving is usually necessary. Planning well ahead for this stage can minimize stress, optimize care and ensure your preferences are carried out.

Take Care and Advocate
A healthy diet and ample exercise can help you live optimally with Parkinson’s. Palliative care can, too. Sometimes mistaken for end-of-life care, palliative care is holistic, team-based therapy to support your quality of life from diagnosis onward.

If something stands in the way of living your best life with Parkinson’s, speak up. People with PD often hesitate to talk about seemingly taboo challenges — hallucinations, urinary incontinence or intimacy issues. It is important to share these quality-of-life issues with your care provider. They are often manageable and can sometimes be as simple as adjusting a medication.

This article is based on a Parkinson’s Foundation Expert Briefings Webinar, The Parkinson’s Journey: Understanding Progression, presented by Annie Killoran, MD, MSc, at University of Iowa Hospitals and Lance M. Wilson, MSS, LSW, C-SWHC, ASW-G, at Jefferson Health Comprehensive Parkinson’s Disease and Movement Disorders Center; both employers are Parkinson’s Foundation Centers of Excellence.

Register for our upcoming Expert Briefings webinars at Parkinson.org/ExpertBriefings.
Care Partner Grief: 8 Ways to Care for Yourself During Bereavement

Grief for a Parkinson's care partner does not begin when your loved one with Parkinson's disease (PD) passes away; it changes shape. To some degree, grief has been a familiar emotion from diagnosis.

As a care partner you grieved alongside your loved one as they faced the difficult parts of PD, while also offering them hope and support. You may have attended exercise classes, advocated for better care and endlessly searched for new resources. You saw your loved one for who they were as a whole person.

Now that your loved one has passed away and you are navigating this new shape of grief, consider how your care partner skillset may help you at this tender time. Here are eight ways to draw upon what you already know from caregiving:

1. Just as you probably encouraged your loved one to do, allow yourself to grieve. Try to maintain hope that you can make it through this.

2. Do what you can to treat your body kindly, as your body holds your grief and needs to heal, too.

3. Visit your primary care doctor for a check-up if you have not been able to tend to your own health lately.

4. Learn what you can about grief. Find resources that work for you.

5. Think about who can be on your grief care team. This could be any combination of family, friends, neighbors, members of your spiritual or virtual communities, a bereavement counselor or social worker, or a support group.

6. When you feel ready, ask your grief care team to help you reconnect with life outside PD and to help you find the little pleasures that make these hard days easier.

7. Remember your loved one for who they were as a whole person. Acknowledge the gifts they brought into your life and ponder what values of theirs you want to bring with you into your future.

8. Be gentle and kind to yourself. Parts of your care partner experience may have looked nothing like what you envisioned; trust that you did the best you could. If it feels right, stay active with your Parkinson's community, as other care partners can benefit from your expertise. Otherwise, allow yourself to create distance.

Tom Manak is newly adjusting to life without his late wife, Ro, who lived with Parkinson’s. “The pain of losing Ro is still fresh,” Tom said.

“It’s okay that you are not okay. The pain of losing a loved one is and will always be part of your normal. No one can tell you that your pain is wrong. Do what’s best for you.”

- Tom

Every care partner had a unique relationship with their loved one with PD and offered them support in unique ways, which means every care partner will have a unique grief journey. Remember to take the advice from others that helps and leave behind what does not feel right to you. Give yourself the time and space to grieve at your own pace, in your own way.

For more resources related to helping you process grief, visit Parkinson.org/Grief.
Board Members Help Us Get Closer to a Cure

Penn Egbert (pictured at left) and Josh Raskin (pictured at right) have two different experiences with Parkinson’s disease (PD) that led them to ultimately join the Parkinson’s Foundation Board and co-chair Reach Further, a $30 million campaign that will accelerate progress on Parkinson’s research and increase access to quality-of-life programs.

While Penn’s father received a fast Parkinson’s diagnosis and expert care from the beginning, Josh later found out his father’s more difficult PD experience may, unfortunately, be the more common one. “I feel my father would have been diagnosed faster, had more time, better quality of life and a huge support system had we found Parkinson’s Foundation resources early on,” Josh said.

Together, Josh and Penn will help the Foundation reach its ambitious $30 million goal to accelerate new treatments through research, expand care and essential programs to more people in the PD community.

“Reach Further will allow us to make sure everyone in our community has access to better care no matter where they live,” Penn said. “This campaign is the next step to continue to build on all our resources, programs and research initiatives.”

A cure remains at the core of Josh’s and Penn’s passion for the Foundation — in honor of their fathers. “Reach Further will move forward the PD GENEration study and critical Foundation research grants. This research is not a moonshot approach, it is going on right now and will help us understand Parkinson’s from the start. This research will create results that will be leveraged by everyone currently looking for a cure,” Josh said.

Help us advance research, improve access to clinical care and meet a rising demand for community-based programs. Donate today at Parkinson.org/Reach.

SUPPORT THE FIGHT AGAINST PARKINSON’S

Make a difference in people’s lives and create a meaningful legacy through planned giving.

A bequest is one of the most popular and flexible ways you can make a gift through your will or trust that helps further the work of the Parkinson’s Foundation. We have partnered with FreeWill, which allows you to write your legal will online, at no cost.

FREEWILL.COM/PARKINSON

GIVE ONLINE TODAY