

**4** Long-distance  
Caregiving

**6** Gadgets  
for PD

**12** Caregiving  
in a Crisis

# PARKINSON *Pathfinder*

FALL 2024

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The **Care Partner** Issue

**apda** AMERICAN  
PARKINSON DISEASE  
ASSOCIATION

NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

FALL 2024

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### COVER

Thanks to **Kerry Howard** (photographer and former APDA Optimism Award winner), model **Rebecca Albert**, and her certified SEADOGS search and rescue dog Tilli, and puppy in training, Kip.

Taken at Riverview Senior Living in Juneau, AK, where APDA Northwest held their SE Alaska Parkinson Disease Education Day in October, 2024.

To learn more about the incredible work of the SEADOGS please visit their Facebook page at [Facebook.com/seadogs907](https://Facebook.com/seadogs907)



Strength in optimism. Hope in progress.

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## OUR MISSION

Every day, we provide the support, education,  
and research that will help everyone impacted by  
Parkinson's disease live life to the fullest.



**November is not only National Family Caregivers Month, but also a time to reflect on gratitude – which is the perfect opportunity to combine the two and dedicate this issue to the care partners who have joined loved ones on their Parkinson’s journey.**

When someone receives a Parkinson’s diagnosis, the impact is felt by the entire family. November is not only National Family Caregivers Month, but also a time to reflect on gratitude – which is the perfect opportunity to combine the two and dedicate this issue to the care partners who have joined loved ones on their Parkinson’s journey.

I am constantly inspired by families who, despite the challenges brought on by Parkinson’s, find ways to stay strong and connected. These care partners don’t just provide assistance, they join their loved ones in learning about the disease, building their support networks, and developing healthy habits – all so they can be better prepared for what tomorrow may bring.

No one pretends that caregiving is easy.

I am reminded of the powerful poem *Caring* by Pete and Anne Beidler, which captured her raw truth of caregiving for her husband in the later stages of PD: “Being your caregiver smears me all over / With lonely juice and / Angry juice and / Self-pity juice and / Resentment juice and / Very, very much sadness juice. / Caregiving almost swallows me up.” Yet after some soul searching - and a little self-care - she finds renewed strength and love: “But wait a minute. / Time to wash my face and / Take a nap and / Muster up a smile and / Let myself remember how / I really love you.” My favorite line of the poem brings it all together with, “And I begin to make / some grateful juice.”

Let’s all make some “grateful juice” and celebrate our care partners. In this issue, you’ll find four articles dedicated to caregiving – we hope you find them informative and inspiring.

With gratitude,

Kirsten Richards, Executive Director

*NOTE: The poem Caring in its entirety appeared in our spring 2020 issue. Pete Beidler passed away with Parkinson’s in April 2023.*

## **In 2025 APDA is connecting, educating, and empowering care partners with a new multi-week support series.**

This is new APDA signature series has been designed to provide caregivers tools and connections to take care of themselves while caring for someone with PD.

**\$200**  
pays for  
one session

**\$1600**  
pays for full  
8-week series

**Any donated amount goes towards providing education and resources for those who need it most.**

Donate at  
**[apdaparkinson.org/Northwest](https://apdaparkinson.org/Northwest)**  
or send a check to **APDA**  
**130 Nickerson Street, Suite 300**  
**Seattle, WA 98109**



# Caring for Our Loved Ones with Parkinson's

By **Katie Freeman, MSW**

*Katie Freeman, MSW, is a social worker and APDA Northwest's Manager of Programs and Community Engagement. They support Parkinson's caregivers by facilitating support groups, offering one-on-one consultations, leading educational programs, and providing information and referral services. Below are Katie's answers to a few questions commonly asked by caregivers:*

## What do I call myself? Caregiver? Caretaker? Care Partner?

It may seem like semantics, but these terms reflect the relational dynamic and philosophy of care between a person with Parkinson's and the people responsible for their care. Think about the power dynamics implied in the

words **take** versus **give** versus **partner**. Taking or giving is something you do **to** someone while partnering is something you do **with** someone.

Caregiver is generally considered the most neutral term and can refer to a close family member or a paid professional who cares for a person with Parkinson's. Care Partner is typically reserved for a spouse or family member who partners with their loved one with PD to manage their care. Caretaker has become less popular over the years, but it's often used interchangeably with caregiver.

For some of us, the distinctions between these terms are meaningful and important, while others don't care as much. Just know that there is no right or

wrong way to refer to yourself; it's simply a matter of what feels true and genuine for you and your loved one with Parkinson's.

## What does caregiving look like throughout the different stages of PD?

Your doctor may have told you that there are five stages of Parkinson's, based on a staging system created by Drs. Hoehn & Yahr in the 1960s. While it has some flaws, this staging system can help us understand how Parkinson's motor symptoms progress over time. With each stage of Parkinson's, there is a corresponding stage of caregiving. Expect your role as caregiver to evolve over time as Parkinson's symptoms progress and your loved ones' needs change.

## The Five Stages of Parkinson's

This is based on a staging system created by Drs. Hoehn & Yahr in the 1960s. While it has some flaws, this system can help us understand how Parkinson's motor symptoms progress over time.

	STAGE 1	STAGE 2
Person with Parkinson's	<ul style="list-style-type: none"> <li>Mild symptoms that generally do not interfere with daily activities.</li> <li>Tremors and other movement symptoms occur on one side of the body only.</li> <li>Changes in posture, walking and facial expressions.</li> </ul>	<ul style="list-style-type: none"> <li>Increased symptoms make daily tasks more difficult and lengthy, but person is still able to live alone.</li> <li>Tremors and other movement symptoms occur on one or both sides of the body or the midline.</li> <li>Walking problems and poor posture may become apparent.</li> </ul>
Caregiver	<ul style="list-style-type: none"> <li>Provide emotional support to help process the new diagnosis.</li> <li>Learn about Parkinson's disease.</li> <li>Start having conversations about the future.</li> <li>Help maintain or establish healthy habits around exercise, nutrition, sleep and general health maintenance.</li> </ul>	<ul style="list-style-type: none"> <li>Help adjust to physical changes and learn new ways of completing daily tasks.</li> <li>Accompany on medical appointments.</li> <li>Participate in PD caregivers support group.</li> <li>Maintain healthy habits and encourage care receiver to do the same.</li> <li>Share or transfer household responsibilities.</li> <li>Figure out what care/help you can expect from loved ones.</li> </ul>

**I feel overwhelmed, burnt out, and powerless. How can I motivate myself to keep going?**

Caregiving can be a way that we show love, respect, and gratitude to the people in our lives who have Parkinson’s. But it can also be challenging work that impacts our physical, emotional, and spiritual health. In those moments when you feel the most overwhelmed and powerless, remind yourself that you have a choice in every situation. Am I going to help this person? Or am I going to walk away? For many of us, the idea of walking away is unthinkable. But the reality is that people choose not to care every day.

Instead of doing that every day, you wake up and choose to care. You choose to help someone who is vulnerable. You choose to ensure that this person is safe and their needs are met. You put your values into action. And I’m so grateful for all of you making that choice.

Once you’ve gotten through that moment of emotional intensity, the next step is to pick up your phone and ask for help.

**How do I ask for help?**

Caregivers often have the hardest time asking for help. Many of us pride ourselves on our ability to care for others and don’t want to admit that we can’t do everything. We can often assume that other people won’t understand what we’re going through or that it’s a burden on someone else if we ask for their help. We don’t want to interfere with our children’s or friends’ lives.

However, most of us have people in our lives who want to help but don’t know how. Have open and honest conversations with these people about the specific tasks that you need help with or the kind of support you need. Let your friends and family tell you what they are able to offer. Communication is key here on both sides.

Remember that helping out feels good! Just like you find meaning in caring for your loved one with Parkinson’s, others will find meaning by helping you. Give your loved ones the opportunity to help. For many, that invitation to help will be a gift and an invitation to be closer to you and your loved ones with Parkinson’s.

Do you have questions about caregiving? Need some extra support or connections to local resources? Reach out to Katie via phone and email, or set up a one-on-one consultation.

[kfreeman@apdaparkinson.org](mailto:kfreeman@apdaparkinson.org)  
206.695.2905  
[bit.ly/ConsultationsWithKatie](https://bit.ly/ConsultationsWithKatie)



**Katie Freeman, MSW** is the Manager of Programs and Community Engagement for the Northwest Chapter of the American Parkinson

Disease Association. As a geriatric social worker, they help members of the Parkinson’s community get connected to local resources and find new ways to live their best lives with Parkinson’s disease. Katie’s interests include cognitive health and wellness, community building, and health equity. They are a skilled support group facilitator, public speaker, and advocate for older adults with neurodegenerative disorders.

STAGE 3	STAGE 4	STAGE 5
<ul style="list-style-type: none"> <li>• Characterized by loss of balance and increased falls.</li> <li>• Needs minor assistance with daily activities, but still able to maintain independence May no longer be able to live alone safely.</li> </ul>	<ul style="list-style-type: none"> <li>• Still able to walk and stand independently May need to use walker or cane to maintain safety.</li> <li>• Needs increased assistance with activities of daily living.</li> <li>• Unable to live alone safely.</li> </ul>	<ul style="list-style-type: none"> <li>• Unable to stand or walk due to increased stiffness and/or other movement symptoms Uses wheelchair or stays in bed.</li> <li>• Requires 24/7 care with activities of daily living.</li> </ul>
<ul style="list-style-type: none"> <li>• Assist with IADLs such as meal planning and prep, managing finances, transportation, medication management.</li> <li>• Help facilitate social engagement, recreation and exercise.</li> <li>• Modify home to be more accessible and prevent falls.</li> <li>• Maintain personal health and wellbeing.</li> <li>• Ask for help from loved ones.</li> <li>• Interview professional caregivers and/or tour care communities.</li> </ul>	<ul style="list-style-type: none"> <li>• Take over all IADLs and assist with ADLs such as bathing, grooming, dressing, eating.</li> <li>• Facilitate exercise, socialization and cognitive stimulation.</li> <li>• Provide emotional support to help accept increasing disability and need for care.</li> <li>• Find opportunities for respite and continue personal health maintenance and wellness habits.</li> <li>• Receive help from loved ones.</li> <li>• Begin transition to long-term or 24/7 care.</li> </ul>	<ul style="list-style-type: none"> <li>• Fully transition to long-term or 24/7 care. Handle all ADLs and IADLs (with assistance from professional caregivers).</li> <li>• Advocate for care receiver in medical settings.</li> <li>• Make medical and financial decisions (if POA) When necessary, establish end-of-life care Attend to personal health and care needs Seek emotional and spiritual support from loved ones and professionals.</li> </ul>



# Long Distance Caregiving: Supporting a Loved One with Parkinson's Disease from Afar

By **Lianna Marie**

For a few years during my mom's journey with PD, I cared for her while living 2,500 miles away. I won't lie — it was tough. When I lived nearby, it was much easier to know how she was doing and assess her needs. Though I tried my best to keep up to date with her health and to help her via phone, sometimes it felt like it wasn't enough.

I went through all kinds of emotions, including guilt over not being able to visit more often, frustration over not being able to help as much as I once could, and worry over the level of care she was receiving. I struggled with letting go and depending on others to care for her.

If you're a long-distance caregiver, you can probably relate to some of this. Maybe you spend your long weekends or vacations visiting your loved one, hoping and praying that they'll still be okay each time you visit. You're not alone. A recent study (1) found that up to one-third of all caregivers care for their loved ones from a distance and most struggle with the things I just mentioned.

Though there will be challenges along the way, the following are some things you can do to make caring for your loved one from a distance easier.

## 1. Establish a Local Support Network

Building a reliable local support network is one of the first steps in long-distance caregiving. This network may consist of family members, friends, neighbors, and paid caregivers who are geographically closer to your loved one. Ensure that everyone involved knows their roles and has your contact information. Check in with them regularly to stay informed about any changes in your loved one's condition.

Local support should also include healthcare providers. Maintain close communication with your loved one's doctors, neurologists, physical therapists, and other specialists. Sign up for online patient portals to access medical records and stay updated on appointments and treatments.

## 2. Leverage Technology

Technology can be a lifesaver for long-distance caregivers. Video calling platforms like Zoom, Skype, and FaceTime make it possible to check in with your loved one regularly. These visual check-ins can provide reassurance and help you assess your

loved one's appearance, mood, and surroundings.

There are also apps designed to help with medication management, scheduling, and care coordination. Apps like CareZone or Medisafe allow you to track medication adherence, manage doctor's appointments, and store important health information, all of which can be shared with your loved one's care team. Additionally, wearable devices that monitor health metrics, such as heart rate or mobility, can offer real-time data that is accessible remotely.

## 3. Stay Informed About Parkinson's Disease Progression

Understanding the stages and symptoms of Parkinson's is crucial for long-distance caregivers. As the disease progresses, symptoms can fluctuate, and new care needs may arise. Educate yourself on the different aspects of the disease, from motor symptoms (tremors, rigidity, slowness of movement) to non-motor symptoms (cognitive changes, mood disturbances, sleep problems). Knowing what to expect can help you plan ahead and make informed decisions regarding your loved one's care.

Keep in touch with their healthcare team to stay updated on changes in medication, therapy, or care recommendations. If you're not able to attend medical appointments, ask if you can join by phone or video.

**Stay up to date on happenings through our weekly email: News You Can Use, our educational website, or subscribe to our YouTube channel, [Youtube.com/APDANorthwest](https://www.youtube.com/APDANorthwest)**

## 4. Hire Professional Help When Necessary

For many long-distance caregivers, hiring professional help becomes necessary at some point. This could include home health aides, personal care assistants, or even a professional care manager who can coordinate services and act as your local liaison.

A geriatric care manager, in particular, can be an invaluable resource. They are trained to assess needs, recommend services, and help navigate the healthcare system. A care manager can also update you on your loved one's condition and alert you to any changes requiring immediate attention.

It is important to note that not all geriatric care managers are required to be certified by their state or the federal government, so make sure that you interview them yourself and do a

thorough check with their organization before hiring them.

If necessary, hire an elder law attorney to ensure that your loved one's finances and insurance needs are taken care of.

**For more information on care managers serving the Northwest: [Aginglifecare.org](https://aginglifecare.org)**

## 5. Create a Comprehensive Care Plan

A clear, written care plan is essential for ensuring everyone involved in your loved one's care is on the same page. This document should outline medical information (including medications and doctors' contacts), daily routines, dietary restrictions, and any special mobility or cognitive challenges instructions.

Make sure this care plan is easily accessible to all local and remote caregivers. Update the plan regularly, especially after doctor's visits or changes in your loved one's condition.

## 6. Make the Most of Visits

When you can visit your loved one, try to make the most of your time together. Focus not only on their immediate care needs but also on their emotional well-being. Spend quality time together and engage in activities they enjoy, whether taking a walk, listening to music, or simply having a meaningful conversation.

While you're there, assess their living environment to ensure it's safe and comfortable. Are there potential fall hazards? Is the house well-maintained and clean? Does your loved one have easy access to necessary items? These considerations may be harder to gauge from a distance but are essential to their safety.

If your loved one has Parkinson's dementia, it's likely they do not connect with you the way they used to when you visit. Many long-distance caregivers find this painful and wonder if their visits are still valuable.

I experienced this while visiting my mom in the nursing home. A few times, she'd been so agitated that I questioned whether my being there made a positive difference. That's when I reminded myself I wasn't there just to visit.

I used some of my time to talk with the nurses, personal support workers, and volunteers who were all part of Mom's care team. This helped me get a better idea of how she was doing on a day-to-day basis and in what ways I could help her. Something as simple as finding out that she needed long socks (her short ones kept falling off during episodes of dyskinesia) made me feel better, as it gave me something specific that I could do to help her.

I also was able to speak to her doctor, who agreed to make a medication change (I had discovered that Mom had been given unnecessary pain meds for a fall months earlier) and to her physical therapist about making changes to her wheelchair to make it more comfortable for her.

## 7. Practice Self-Care (a.k.a. be kind to yourself!)

Caring for someone with Parkinson's from afar can be emotionally and mentally taxing. It's easy to feel guilt or worry when you can't be physically present. However, it's essential to recognize that you're doing your best under the circumstances. Make sure to carve out time for your own self-care, whether

that's taking a break, seeking support from other caregivers, or speaking to a therapist.

Staying connected to your loved one doesn't mean sacrificing your own well-being. By prioritizing your health and managing your stress, you'll be better positioned to provide effective, long-term care.

**Start with the basics — get enough sleep, exercise regularly, eat nourishing foods. Then beyond that, find time to do what you value the most.**

## 8. Be Kind to Your Loved One's Care Team

Let those caring for your loved one know they are appreciated. Whether it be something as simple as a thank you card, flowers, or something more elaborate like a gift basket, such shows of appreciation can mean a lot to someone who may be tired from all the demands of caregiving.

## 9. Join a Support Group

Long-distance caregiving can sometimes feel isolating, but you're not alone. Consider joining a Parkinson's disease support group for caregivers, either in person or online. These groups offer a sense of community, and you can gain valuable insights from others who are facing similar challenges. Some groups also invite guest speakers, such as doctors, social workers, and therapists, providing expert advice on managing Parkinson's care.

APDA NW has both in-person and online support groups for care partners. **You can find more information by visiting [apdaparkinson.org/community/resources-support/support-groups](https://apdaparkinson.org/community/resources-support/support-groups) or by calling Katie Freeman, MSW, at 206-695-2905**

## Conclusion

Caring for a loved one with Parkinson's disease from a distance requires careful planning, open communication, and the right tools. By building a local support network, utilizing technology, staying informed about the disease, and ensuring a structured care plan is in place, you can provide compassionate and effective care, even from afar.

Remember that caregiving is a team effort, and while you may not be there in person every day, your presence in your loved one's life remains invaluable.

### Study source:

"Caregiver Statistics: Demographics," Family Caregiver Alliance: National Center on Caregiving, <https://www.caregiver.org/caregiver-statistics-demographics>.



**Lianna Marie** served as her mother's caregiver and advocate for over 20 years through the many stages of Parkinson's disease. She currently serves as APDA's Regional Director of Marketing and Communications and spends her free time writing books to help the Parkinson's community worldwide.



# GADGETS FOR PD

There are a multitude of adaptive equipment and devices on the market that can help simplify the daily challenges of living with Parkinson's disease or can provide assistance to someone caring a loved one with PD.

Below are some examples that came from our readers.

*Disclaimer: These are reader suggestions and do not represent an APDA endorsement of a particular device. Please consult with a medical professional for suggestions on the best adaptive equipment.*



shoes and now only wear **Hoka shoes**. Both have saved me from potential falls.” —*Nick P.*

“My wife saw my balance issue and recommended that I wear yoga socks with sticky bottoms. I also gave up on regular

“I have recently purchased an **auto cane**, which helps my husband get out of the car easier. Auto Cane - Able Life Solutions” —*Roy G.*



“We were going to get my husband a call button to wear in case he falls, but he strongly resisted. Instead, we got him an **Apple Watch**. If he needs help, he can say to the watch, “Hey Siri, call my wife” or “Hey Siri, call 911,” and it will do so. This solved the safety issue and kept him from feeling like an invalid.” —*Cathy R.*



“For better days walking (PD makes for unpredictable mobility), this walker allows for brief sitting or wheeling when necessary: **Nitro Duet Rollator** and Transport Chair. It combines a walker and a wheelchair. There are also (albeit pricier) scooter options that fold up, making farmers markets, walks, museums- poor balance limits easier: **MovingLife Scooter**. We also find that **Trekking poles** work well too, for times a walker or scooter doesn’t work. —*Darla L.*



“Something we have found helpful is the **Lundberg Bed Rail**. This helps my husband get in and out of bed, and also helps him stay ON the bed, by clearly marking the edge of the mattress. (He has developed a tendency to sleep on an angle, near the edge the bed, and has fallen out once - which was one too many times!). Easy to install and surprisingly solid. Also has a helpful motion-sensing light and a pocket for book or phone.” —*Anonymous*







## Occupational Therapy & PD

Parkinson’s disease can introduce all types of challenges into daily life that can interfere with your quality of life. Teaching you new techniques and helping find modifications or helpful tools to make daily life easier and safer is the role of an Occupational Therapist.

Occupational therapy (OT) is a branch of rehabilitative medicine that focuses on the performance of the activities required for independent daily living. Occupational Therapists are experts in devising ways to help you maximize your movement and quality of life – or as Occupational Therapist **Heidi Huynh** from Ascend Therapy services (pictured above) calls it “I am a trained problem solver”

We asked Heidi to tell us her top 5 useful gadgets that help with making tasks easier and safer.

[www.ascendtherapypnw.com](http://www.ascendtherapypnw.com)



◀ **Foot Funnel** This is Heidi’s top pick as it makes it so easy to get your shoes on and she finds it more effective and easier than a shoe horn.

▶ **Adaptive Laces** helps in lacing up your shoes, especially if you have challenges with fine motor control.



▶ **Stocking Donner** there are lots of different types of stocking donners and if you use compression stockings they can be quite useful. Heidi’s favorite type are the ones with extended handles and hinges because you can angle it differently to get your foot in easier.

▶ In the bathroom, for safety in the shower Heidi likes **Traction Strips** or **Stick on Decals** for the shower floor. She prefers these over shower mats as they can be a maintenance challenge. With strips or decals, they just become part of the of the tub/shower, no moving them and no grime building up beneath them. Additionally, Heidi encourages you to think about the mat outside your shower and make sure it has grippy material on the bottom so it adheres to the floor to prevent slippage.



For something that has many uses, Heidi suggests a variety of **Grip Assists**. You can build up the handles for anything that you may find challenging to hold – utensils, paint brushes, writing instruments, toothbrushes, etc.

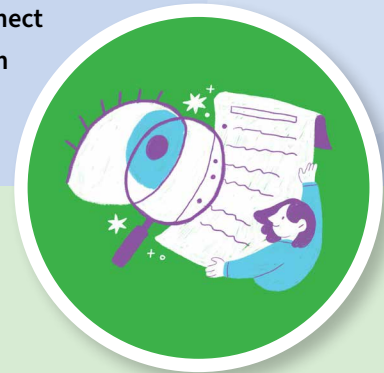




# CONNECT

APDA creates opportunities for social connections that can help boost physical health, improve mental health, and increase overall well-being.

- Support Groups
- Women with PD
- Young Onset PD
- Atypical Parkinson's
- Spanish speakers
- Exercise and Wellness classes
- DBS Connect
- Optimism Walks



# 2024

## A year of Impact, Optimism, and Progress

In 2024, APDA Northwest dedicated itself to enhancing the lives of people impacted by Parkinson's through high-quality education, crucial support, vital research, and building community around our 5-state region. Living and working in the PNW enables us to engage with the PD community directly so we can identify and address areas where we can make the most meaningful difference.

# EDUCATE

APDA empowers people living with PD at every stage, from newly diagnosed to those further along the journey. We provide education opportunities and connect individuals with valuable resources to help them live life to the fullest.

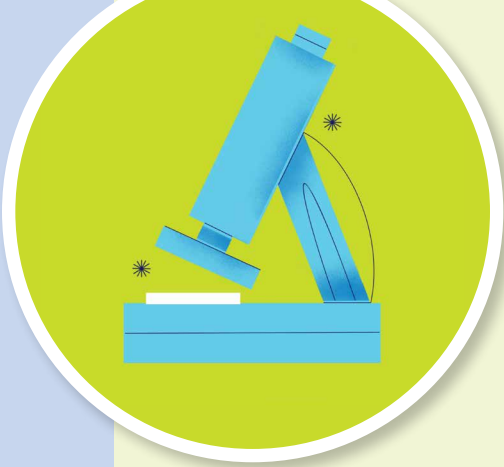
- Newly diagnosed packets
- *Parkinson Pathfinder*
- PD Essentials
- Live Well symposiums
- Good Start for newly diagnosed
- Downloadable education materials
- Parkinson's Education Days

# SUPPORT

APDA connects people to valuable resources, while building, strengthening, and sustaining a sense of community and support.

- PRESS support series for newly diagnosed
- PRESS ON support series for advancing PD
- Social Worker Office Hours
- Care Partner support series
- Professionally-led support groups
- Training and support to volunteer-led group leaders





# RESEARCH

APDA proudly invests in the most promising clinicians and scientific projects focused on the discovery of the cause and finding the cure for PD.

- Awarded \$2.6M to support PD research
- Fully fund Parkinson disease Research Registry
- Hosted 6-week guitar research study in office
- Promote local opportunities to participate in research

# WELLNESS

APDA recognizes the importance of nutrition, exercise, and overall wellness as key to combatting the challenges brought about by PD and improving quality of life.

- **Beyond Medication: Wellness Series**
  - Finessing Fine Motor Skills
  - PD-PRO Nutrition
  - Beat the Freeze
  - Hands on Helpful Caregiving
- Free exercise classes
- Connecting through Art



# COMMUNITY

APDA fosters community to ensure that everyone impacted by Parkinson’s has access to the information they need, wherever they live. In 2024 we traveled throughout the Northwest, hosting education days, visiting support groups, and engaging in outreach and awareness events.

- South Puget Sound
- Port Angeles
- Boise
- Juneau
- Kalispell
- Coeur d’Alene
- Portland
- Seattle
- Tacoma
- North Puget Sound
- Olympia
- Wenatchee
- Bellingham

# Flying Solo with Parkinson's *(And yes, I'm the Pilot)*

By **Stacy Anko**



**Every day, I wake up and take a step through two faces: one is a person with Parkinson's, and the other is her caregiver. The two faces are my own.**

If you've ever wondered what it's like to wake up every morning and have a conference call with yourself—both the Parkinson's patient and her overworked caregiver—well, welcome to my world. It's not glamorous, but it sure is... interesting. Let me tell you how I've managed to stay upright (mostly) without a life partner sharing my space—and how AI has become one of my co-pilots on this journey.

Let's start with the truth: my house looks like a disaster zone half the time, and I'd love to blame the two lovely women who help me for that. But no, it's all me—master of chaos, creator of obstacle courses, and fire hazard extraordinaire (Like the iron or stove I keep forgetting to turn off!). Living alone with Parkinson's has made me an expert at both creating and avoiding hazards. It's a talent, really.

Dangerous? Sure. But this is my reality, and I am not giving up. I feel very fortunate to be living this

journey in an age where technology makes almost everything easier. AI is helping me declutter my world, build a time management system (meds, PT, pain... the list goes on), a personal relationship manager (think address book on steroids), a home inventory so I know where to find things and annual list of tasks (i.e., home maintenance, spring cleaning, bills...) that are all managed by an AI-powered assistant that keeps track of everything. It sends reminders for meds, helps me track symptoms, and even lets me know when it's time for a break.

Now, I'd love to tell you that I'm always stoic and brave, but the truth is that some days, I want to stay in bed and have someone there to take care of me.

Managing PD alone means the emotional roller coaster has no seatbelts, and all the dips are steeper than expected. I use mood-tracking apps, which have been a game-changer for me. They help me understand my emotional patterns and give me a nudge when I need to refocus. If I'm in a slump, an AI-guided mindfulness app offers exercises to get me back on track. These tools don't replace a care partner, but they help me care for



APDA recently hosted a webinar in which individuals shared the unique challenges and strategies of living with Parkinson's disease without the support of a family care partner.

The webinar, **Unlocking Strength Within: Navigating PD Without a Life Partner**, can be found on APDA's YouTube Channel.



I'd love to tell you that I'm always stoic and brave, but the truth is that some days, I want to stay in bed and have someone there to take care of me.



APDA's PRESS™ (Parkinson's Roadmap for Education and Support Services) was designed for those diagnosed with PD within the last 5 years.

This eight-week program, conducted in a support group format, will help you feel empowered, in control, and optimistic. The PRESS™ program was designed to provide emotional support and a safe place to share coping strategies to live your best life with PD.

Our next program will take place in January 2025. Visit [apdaparkinson.org/Northwest](http://apdaparkinson.org/Northwest) or call us for more information.

myself through knowledge and access to many tools that make my life easier, which is half the battle.

I've recently added a video recording system that tracks my movements in the house, just in case I trip over one of my carefully placed obstacles or have a walkabout while sleeping. A few friends have access to make sure I am alive and well. There are also an array of other smart home devices that can help navigate this chaos—there are too many to list.

Managing my world alone is one thing, and I would be remiss for not mentioning more about my other co-pilots. After my diagnosis, I knew I needed help, but let's just say that the feeling of overwhelm following a Parkinson's diagnosis is real.

My movement disorder specialist? Hero. Using all my physical & occupational therapy credits in two months? Redefining. The Press Program at APDA Northwest? Lifesaver. Day One: Breaking out from the Parkinson's Prison Cinema Therapy through [Yesandexercise.org](http://Yesandexercise.org). Heroic. And don't get me started on the magic of the right medication—it's the only

reason I'm not currently starring in a one-woman comedic drama called *Did I Tell You I Have Parkinson's?* (No, seriously).

I've got my family, but I also have a close-knit "chosen family" in my world—though it's more like a soap opera cast of world travelers, ex-boyfriends, and business partners—they help me when things get tough. So, while I may not have a traditional care partner, I've got my crew. And yes, I rely on them heavily because flying solo doesn't mean flying without a safety net.

I've learned to lean on my healthcare team, trust in community, and laugh at the chaos along the way. And with a little help from AI, I'm creating a future that's not just survivable but sustainable.

So here I am, flying solo with Parkinson's, and while it's not always pretty, it's definitely been a journey worth sharing. For anyone else out there juggling Parkinson's and independence, know this: it's possible, it's tough, but it's also full of small victories (and the occasional hilarious disaster).



**Stacy Anko** is a writer and advocate using her journey with Parkinson's Disease as a platform to inspire and empower others. Through her upcoming blog, *The Monkey Manifesto*, Stacy focuses on the creative ways she integrates AI into her life, from managing her condition to maintaining independence. Her writing draws not only from her experiences with Parkinson's but also from her rich history as an unconventional global citizen. Her upcoming articles, blog, and book will deeply explore her life journey, offering insights into navigating life and Parkinson's without a care partner. Learn more at [StacyAnko.com](http://StacyAnko.com).

# Caregiving in a Crisis:

## ONE FAMILY'S JOURNEY

By **Suzanne Cameron**

In 1979 I met my soulmate Chris, a Deadliest Catch fisherman. He fished the Bering Sea for king crabs, but after losing many friends to the ocean, we decided to make a change.

We bought a Bristol Bay salmon boat, moved to Seattle, and started a family. Things were going swimmingly. We were young, busy with our kids, involved in various school activities, and I had opened a small restaurant.

Chris Jewell riding the Seattle to Portland (STP) bike race.



We thought we were in control of our destiny.

In 1998, after some troubling symptoms, Chris was diagnosed at age 39 with Parkinson's. Here was a guy who

had never been sick for a day since I'd known him. He was the guy who could fix anything but a broken heart and a busted ass.

At the time of Chris's diagnosis, we were very involved with our sons' school, and when the school needed new computers or playgrounds, we jumped in to raise money to solve the problem. I thought if I applied this model

to Parkinson's, I could make this problem go away. After all, everyone told us when Chris was diagnosed that there would be a cure in five years. We were going to help speed up that timeline.

We dove in, chairing walkathons, hosting an annual neighborhood party in our backyard, and founding the Magic of Hope Gala in 2003. We raised lots of money and educated all our friends about Parkinson's in the process.

Chris did an admirable job of managing his Parkinson's journey by staying active. He did this by cycling, swimming, gardening, and remodeling our home. He cycled the Seattle to Portland (STP) ride for 17 years with family and friends, with my business, Cameron Catering, providing support and feeding upwards of 200 riders each day.

He retired from work in 2014. Despite his valiant efforts, PD caught up with him in 2022. Balance and speech became extremely difficult; then came the continued falling. Fortunately, nothing broke, but he was very banged up.

December 2023 brought the beginning of a series of terrible events. Chris began suffering from hallucinations and psychosis; a complication from PD we only peripherally understood. His movements were wildly impulsive, and the falling got way worse. We worked with the neurologist, adjusted some medications, and things improved. I met with social workers and palliative care where we discussed our end-of-life plans,

Suzanne, Chris, and sons Pat and Sam on their last family fishing trip in Alaska.



and I also learned that Medicare covered in home OT, PT, and Speech home health, so I began scheduling those visits. I brought in full-time care to help so that I could continue running my business. I also needed help at night since Chris was getting up 4-5 times and falling often.

We had five great weeks.

In early April, things blew up very quickly, spiraling into a completely psychotic episode. I called 911, and Chris went to the hospital. He spent 30 hours in restraints, going through something I wished I could unsee.

When the nurses tried to give him meds, he bit the spoon. Chris went without his Parkinson's medication for two days because he was not able to take them orally. We started grinding up his PD meds and feeding them to him through a syringe. I talked to social workers and palliative care, who let us know about the available resources, but there wasn't a lot to help with our specific situation. This was an ugly side of Parkinson's I'd never heard of. Behind the doctors' masks, I could see that they were scared and didn't know what to do.

It was nine days of hell.

My boys and their partners took

## APDA Resources for Advancing PD

APDA has a number of resources for Advancing PD. You can find the resources mentioned below, as well as many others, in the APDA Resource library at [apdaparkinson.org/resources](https://apdaparkinson.org/resources).

### PLANNING FOR THE WHAT-IF'S

A series of blog posts available on the APDA website that addresses sensitive topics to arm you with useful information should you need it now or further down the road.

### CARE PARTNER SUPPORT GROUPS

APDA Northwest offers several care partner support groups and can connect you to community groups throughout our 5-state region. Visit our website or give us a call to find a group that is right for you.

### PRESS ON

A new signature program being piloted by APDA in 2025. Open to those living with PD for 5+ years, this 8-week program will provide education about the progression of Parkinson's disease and planning for the future. It also offers the opportunity for connecting with others with Parkinson's disease for emotional support and sharing. Call our office for more information.

### CARE PARTNER SUPPORT SERIES

APDA Northwest will be piloting a new multi-week support program for caregivers. More information will be available early in 2025, contact our office for more information.

### PALLIATIVE CARE

Palliative care is a medical approach for those with complex illnesses, in which the focus is on maximizing quality of life. APDA has a blog and a webinar dedicated to this topic, available in the APDA Resource Library.

turns spending the night so I could go home and Chris wouldn't be alone. We discovered that it was vital to have someone in the room with Chris at all times. It was important to manage his Parkinson's meds, to have someone present during rounds, to hear any and all updates firsthand, and to have someone in the room to advocate for his needs. The hospital staff were wonderful and well-meaning, but not as knowledgeable about Parkinson's as our family members.

Our supportive tribe of friends started bringing us food. Other friends handled all the texting and communicating of Chris's health updates to our wide network, and having this help and support was invaluable. One less thing for me and our boys to worry about.

And then Chris started to come back.

He was released from the hospital after 9 days, with a long road ahead. He came home unable to move anything, barely speaking. Our friends continued to step up, bringing meals, flowers, and friendship. As a family, together we worked hard to help Chris improve, step by step. He wanted to get on the exercise bike as soon as he could move. I worked with the pharmacologist from the neurology department, having weekly Zoom meetings to tinker with the timing and dosage of medication. Now, after many months of hard work, he is walking with a cane, but he has lots of bouts of freezing and is still wobbly.

He is determined to get back to normal, although we don't know what that is anymore. As a fiercely independent human and self-made man, Chris's loss of the ability to fully care for himself, fix everything, build anything, walk the dog, and travel has been devastating. Yet, in this 26-year journey, I rarely see discouragement or anger.

For our boys and me, it has also been a journey of loss, watching him struggle.

The things Chris experienced this year were very scary for our family and life-changing for him. I would like to be able to find more ways APDA can help people in the later stages of Parkinson's,



Suzanne with a handcrafted quilt that sold for \$15K at APDA event.

specifically with spreading education surrounding managing hospitalizations and dementia/psychosis in PD, so we can all continue to live well. Chris would not have survived without our constant attention to keep him calm, hydrated, fed and medicated, and not everyone has that ability. This is a gap in the system that I'd like to improve.

#### My advice after 26 years:

- Keep it fun, keep living, keep dancing.
- Share your story with everyone everywhere you go. It's surprising how many people have a connection to Parkinson's.
- Understand that despite how much you know or plan, the unexpected can still occur. Review your end-of-life plans through a Parkinson's lens.
- Accept help from your friends.
- Finally, keep your glass half full, even if it's with vodka.

**Suzanne Cameron** and her husband Chris Jewell have been advocating for the Parkinson's community since Chris was diagnosed in 1998 at the age of 39. Over the years, Suzanne has led support groups, planned parties and galas, and helped raise an estimated \$7 million in critical funds for local support, education, and research. Suzanne started Cameron Catering in 2005 and has grown it into a multimillion-dollar, woman-owned business with 75 employees and 500 events annually. Suzanne currently serves as Vice President on the APDA Northwest Chapter Board of Directors. She also handcrafts beautiful quilts in her spare time.



SAVE THE DATE

# MAGIC OF HOPE

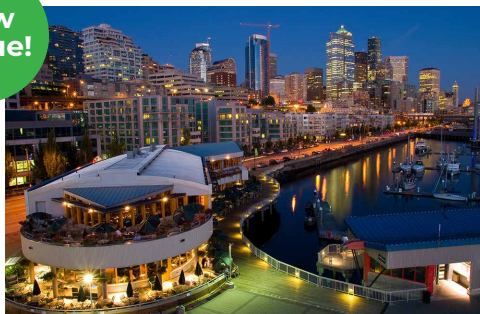
GALA & AUCTION BENEFITING APDA

— STRENGTH —

Saturday, March 8, 2025 | 5:30 p.m.

Bell Harbor International Conference Center — Seattle

New Venue!



Join us on March 8 at our new venue for a festive evening of cocktails, dinner, auction items, and merriment, where you will find many ways to support and celebrate our Parkinson's community! Magic of Hope is our biggest fundraiser of the year, with a lofty goal to raise \$600,000. The funds raised will further

APDA's mission to provide support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

APDA's tagline is *Strength in optimism. Hope in progress.*

**Our Magic of Hope 2025 theme is STRENGTH — because STRENGTH is what unites us. There is STRENGTH in numbers, in compassion, and in the power of community.**

**STRENGTH isn't just about the fight against Parkinson's disease, it's about the people who stand beside each other through every step of the journey. Together, we can amplify this STRENGTH, providing vital support, education, and resources to everyone impacted by PD.**





Above and bottom: scenes from the 2023 Magic of Hope Gala and Auction

At the event, we will be recognizing the 2025 APDA Optimism Award winners. The Optimism Awards honor individuals who embody APDA’s tagline, “Strength in optimism. Hope in progress.” by making a **meaningful impact on the Parkinson’s community** through support, education, wellness, and/or research. Please help us recognize and celebrate the extraordinary individuals who are demonstrating optimism through their important contributions to our Parkinson’s community and providing inspiration and hope for all that can be achieved.

Nominations are open and are due by January 5. For more information, visit [www.apdaparkinson.org/NWOptimismAwards](https://www.apdaparkinson.org/NWOptimismAwards).

**Registration for the Magic of Hope Gala & Auction opens in mid-December. We hope to see you there!**

Can’t make it to Seattle on March 8? Participate in the online auction featuring fabulous items including sports tickets, vacation packages, and restaurant gift cards. We will also be livestreaming the event.



Right: Executive Director Kirsten Richards and Regional Director Jean Allenbach with 2024 Community Optimism Award Winner, Deb Invancovich.



Executive Director Kirsten Richards and Programs Director Jen Gillick with 2024 Service Provider Optimism Award Winners Bill and Nadean Meyer.







**OPTIMISM WALK** AMERICAN PARKINSON DISEASE ASSOCIATION

A deep sense of COMMUNITY was present in late September at our annual APDA Optimism Walks in Seattle and Olympia.

Thanks to the fundraising efforts of walkers across Western Washington, this year's Optimism Walks were a tremendous success!

We exceeded our fundraising goals for both walks and raised just over \$251,000 to pay for local support, education, and research.

**\$251,000+**



SEATTLE CIRCLE OF OPTIMISM



OLYMPIA CIRCLE OF OPTIMISM

We recognized 30 individual fundraisers who each raised over \$1,000 and were awarded Circle of Optimism medals.

**SEATTLE CIRCLE OF OPTIMISM**

1. Wayne Curran \$21,000
2. Suzie Schofield \$15,500
3. Paul Herber \$11,097
4. Sue Bae \$8,244.91
5. Leanne Devitt \$6,872
6. Bill Smersh \$6,310
7. Brian Harris \$5,636
8. Dustin Werner \$4,465
9. Michael St John \$4,355
10. Shirin Sarikhani \$4,304
11. Dave Grosby
12. Jeanne Kieffer
13. Leah Frazier
14. Barbara Gunsolus
15. Amy Wilcox
16. Suzanne Cameron
17. J Howard Boyd
18. Cathy Anderson
19. Anne Tiernan
20. Janet Olson
21. Michael Hanway
22. Peter Lynch
23. Amy Key
24. Kirsten Richards

**OLYMPIA CIRCLE OF OPTIMISM**

1. Helen Miller \$12,304
2. Susan Forson
3. Christie Agtarap
4. Suzanne McMahon
5. James Hudson
6. Jennie Davis



## THANK YOU TO OUR SPONSORS:

### PLATINUM



### GOLD



SEAYOPD  
\$32,863

< SEATTLE

### SEAYOPD

Currently the First Place Team out of ALL APDA Optimism Walks across the US!

## TOP FUNDRAISING TEAMS

SEATTLE >

### NeuroFit Reformers

FIRST PLACE team on Walk day, SECOND PLACE out of ALL APDA Optimism Walks across the country!



NEUROFIT REFORMERS  
\$32,490



CHS FOR COACH MILLER  
\$16,253

< OLYMPIA

### CHS for Coach Miller & PD Friends

Raised TWICE what they raised last year, and TOP TEN nationally

OLYMPIA

### Shake, Rattle and Stroll

(not pictured) started the Olympia walk 3 years ago and are still going strong!

SHAKE, RATTLE, AND STROLL  
\$9,346

**Strength in optimism. Hope in progress.**

130 Nickerson Street, Suite 300  
Seattle, WA 98109

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NEWSLETTER!**

Sign up for our newsletter by visiting our website  
[apdaparkinson.org/Northwest](https://apdaparkinson.org/Northwest) or  
emailing [apdanw@apdaparkinson.org](mailto:apdanw@apdaparkinson.org)

**YES! I want to help pay for support, education, and research that will improve people's lives!**

Please clip and return with your check in the envelope provided in the center of this magazine,  
or mail to us at **130 Nickerson St, Suite 300, Seattle WA 98109**

To donate by credit/debit card, please visit our website [apdaparkinson.org/Northwest](https://apdaparkinson.org/Northwest) or call **206.695.2905**

The Northwest Chapter of the American Parkinson Disease Association is a non-profit 501(c)3 organization. Our tax ID number is 13-1962771.



**ENCLOSED IS MY TAX-DEDUCTIBLE GIFT OF:** \_\_\_\_\_

My company \_\_\_\_\_ will match my gift. I will inform my employer that the  
American Parkinson Disease Association, Northwest Chapter, is the match recipient.

Contact me with information on how wills and bequest can support the Northwest Chapter of APDA.

\_\_\_\_\_  
Donor's name Donor's email address Phone

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Donor's address City State Zip

\_\_\_\_\_  
This gift is given in honor of/in memory of Please notify the above individual(s) of my gift

\_\_\_\_\_  
Honoree's address City State Zip

***Thank you for  
your generosity!***