



PANC

UPDATE

Parkinson Association of Northern California

Building Community for the Journey -- November 2024

PANC SUPPORT GROUPS HERE

Welcome to our new Spanish Zoom Support Group led by Milly Nunez!
Contact Milly [here](#) for additional information.

"I'm thankful for my struggle because without it I wouldn't have stumbled across my strength." — Anonymous

My wife, my community
**A Love Story and
Parkinson's**

by Tom Cadman



Lynda and I met in 1984 while standing in line at the Palms in Davis waiting in line for a concert. I came with a different date, but Lynda and I spent most of the evening chatting. The next night, I went to her house for dinner, and here we are 40 years later and very much still in love. Lyn and I loved to travel plus did a lot of it through my business. We went to France, England, Belgium, St. Thomas and plenty of places in the US. I had a motorcycle, so we also enjoyed some incredible coastal excursions.

Little did we know then in 2009 our lives would change significantly. We started to notice some changes in Lyn about a year or so before. She was having trouble with restless legs and staying awake during the day. We saw a couple of neurologists who wanted to do brain surgery which we didn't feel was right at the time. Then one day she had a crumbling episode in the street while walking with a good friend. Lynda ended up in the ER where the doctor looked at her chart then referred us to movement disorder neurologist Dr. Suketu Khandhar. Little did we know what was in store for us.

We brought Lyn's daughter and sister to support us at the appointment. Dr. Khandhar sat down in front of Lynda, looked her right in the eyes and said, "I saw you walking past my office on your way in here, and you have Parkinson's disease." We were all in shock as we had no idea what exactly was ahead. He indicated that with medication, exercise, and diet, she should begin to feel better and provided us with information to take home. It was clear from these materials that the biggest determinant of her future well-being was in her attitude; Lynda had to get her mindset right.

The next thing I did because of my business background and participation in several non-

profit organizations and associations was thought about who I could contact for support and advice. I searched online and found the Parkinson's Association of Northern California (formerly Parkinson's Association of the Sacramento Valley). I called and learned they had a great deal of information, so I hopped in the car and drove to the office where I met Larry Alver who was heading up the organization at the time.

Larry and I became fast friends and have been since. I also found a Parkinson's support group nearby. It was very helpful plus I met a number of people dealing with the same or similar issues as us. Lynda was slow to accept this diagnosis (which we now know is pretty normal). Over time and with my support and encouragement, she became more open to how our life was changing and what we needed to do to make this new life with PD work for us.

Fast forward to today. PANC now has many support groups, and I participate in Larry's El Dorado Hills group twice a month where we all share our challenges, changes, what is working, and more. I still receive many benefits from the group discussions, especially since we are all on this journey together.

I encourage anyone on this path, PD person and PD care partners, to find a support group or exercise or other PD group that fits the need to experience community – there are many options out there. Maybe the first group doesn't work or the second doesn't connect but continue your search for the right fit because we all need that support. It is crucial to your wellbeing and attitude. Hopefully we all have doctors and other specialists on our teams, but we also need the support from family, neighbors and friends who understand what we are going through.

PANC has a list of support groups on their website so check it out and perhaps start with one that is close to you. Maybe start a new one (contact PANC)? Being part of a support group has led me to a number of caregiver books (that have good and helpful ideas) and many other resources as well. PD is different for everybody so not all the ideas and suggestions might work in your case. Don't stop looking for what will work best for you.

I hope this brief story of Lynda's and our Parkinson's journey can be of help. We have been a unit for 40 years -- almost half of that time has been living with Parkinson's. Every day is a new day, and it's a mystery as far as what lies ahead. For today, we make the best of the time we have together and continue to increase our love for one another and the incredible community that continues to love us back.



Why Bring Support to Your Appointments?

Visiting physicians and healthcare specialists with a care partner when you have Parkinson's disease can be beneficial for many reasons including:

1. **Support and Understanding:** Having your partner present can help them better understand your condition, treatment options, and any potential challenges you may face. This can foster empathy and strengthen your support system.
2. **Communication:** Your partner can help communicate your symptoms, concerns, and feelings, especially if you find it difficult to express yourself during appointments. They can also ask questions you might overlook. *It is vitally important that you are honest and upfront with your provider about your challenges and any changes so they can best assist in your well-being. Downplaying your symptoms is not advisable.*
3. **Shared Decision-Making:** Involving your partner in discussions about treatment plans

can lead to better decisions that consider both of your perspectives and preferences.

4. **Education:** Both of you can learn more about Parkinson's disease together, including its progression, management strategies, and available resources.
5. **Emotional Support:** Managing a chronic condition can be emotionally taxing. Having your partner there can provide comfort and reassurance, making it easier to navigate difficult conversations.
6. **Planning for the Future:** Discussing long-term care and planning with your partner can help ensure that both of your needs and preferences are addressed as the disease progresses.

Overall, a partnership in healthcare can lead to better outcomes and a stronger bond between you and your loved one. Don't miss opportunities to share your precious Parkinson's journey and help ensure you and your struggles and needs are represented.

Open Enrollment for Medicare 2025

The open enrollment period for Medicare in 2025 is available now. [Click here for a guide](#) for people living with movement disorders, including those with Parkinson's disease.



December 15 is the last day to enroll or change Medicare plans for coverage that starts on January 1. **Open enrollment ends on January 15.**



More to Parkinson's® Campaign Addresses Hallucinations

Ryan Reynolds, world-renowned actor/entrepreneur and Parkinson's disease advocate, with Acadia Pharmaceuticals Inc, has launched a multi-faceted disease education campaign, *More to Parkinson's®*, to raise awareness among caregivers, patients and their care providers about a common, yet under-recognized aspect of Parkinson's disease – Parkinson's-related hallucinations and delusions.

Around half of the people living with Parkinson's disease may develop hallucinations or delusions over the course of their disease, but up to 90% of people currently do not proactively tell their physicians about these symptoms. By sharing their experiences caring for Ryan's father, James "Jim" Reynolds, Ryan and his mother Tammy, aim to raise awareness, educate and drive conversation between people with Parkinson's disease, their families and their doctors about how best to talk about and treat these non-motor symptoms.

To learn more, click on MoretoParkinsons.com to find resources, including doctor and family discussion guides, and hear stories from people who have been affected by Parkinson's-related hallucinations and delusions.



Save the Date for the 8th Annual Cancel Out Parkinson's Walk!

Mark **Saturday, April 5** on your calendar for this annual fun gathering that supports PANC and brings community together. The Lion's Club has been hosting this event in honor of the late Robert G. Smith and are already planning for another stellar event. Please plan to join!

Together For Sharon Interview with Harry Starkey

In memory of his mother, Sharon Riff Ackerman, George Ackerman created a website to raise awareness and band together to find a cure for Parkinson's disease.

[Click here to see an interview](#) on his site from PANC Board member Harry Starkey and learn what PANC is up to in the California Central Valley and more.



November Free PD Education & Webinars

Monday, November 18 at 11am

The Parkinson Pandemic, A Call to Action! with PD-Connect

The Parkinson Pandemic as well as numerous new research studies that offer strategies for an optimistic road forward.

[Info and register here](#)

Monday, November 18 at 4pm

Navigating Caregiving as a Couple: Real-Life Experiences and Strategies with the Parkinson Society British Columbia

Explore how couples manage the complexities of caregiving while maintaining their relationships and individual well-being. Strategies for navigating dual roles and balancing caregiving responsibilities with a shared life.

[Info and register here](#)

Wednesday, November 20 at 9am

A Neurological Approach for Parkinson's Disease with Neuro Challenge

How acupuncture techniques can help symptoms of Parkinson's.

[Info and register here](#)

Wednesday, November 20 at 10am

The Essentials Toolbox [When Caring for Someone with PD] with the Parkinson's Foundation

Tips and tools that support everyday PD caregiving challenges. The care partner's toolbox may include tips for self-care, strategies for building support networks and enhancing communication skills.

[Info and register here](#)

Thursday, November 21 at 9am

Year of Momentum: What Parkinson's Research Accomplished in 2024 with the Michael J Fox Foundation

MJFF scientists, staff and other experts review this transformational time in Parkinson's research, discussing the latest in the search for better treatments, advances in our understanding of the disease and more.

[Info and register here](#)

Thursday, November 21 at 11am

Ten Things You Need to Know About Hospice with the Family Caregiver Alliance

The essentials of hospice care to empower family caregivers to make informed decisions and advocate for the best care possible, while receiving essential resources and support to navigate end-of-life care. Learn basic hospice philosophy, when to consider hospice care, the core members of the interdisciplinary team and their roles, who can make a referral to hospice, and who can start and stop hospice care.

[Info and register here](#)

Tuesday, November 26 at 2pm

Addressing Caregiver Needs: Burden, Burnout, and Support for Wellbeing with the Parkinson Society of British Columbia

Focus on the caregiver's own mental and emotional health. Explore the signs of burnout, the impact of caregiving on personal identity and relationships, and effective strategies for managing grief and emotional stress. Gain practical tools and support to maintain well-being and resilience throughout the caregiving journey.

[Info and register here](#)

Thank you to Stanford Parkinson's Community Outreach for providing information in this section.

* Contact Jan Whitney [here](#) if you are interested in placing a sponsor article in the *Update*.

www.panctoday.org

Ways to Support

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