

## Care Partner: Bernard

I am one of nearly 40 million care partners across the United States. In 2018, my wife, Denise, was diagnosed with Parkinson's disease after nearly 15 years of knowing something was wrong. For me, raising awareness of the diversity of Parkinson's patients is personal.

Living with someone who has Parkinson's disease is emotionally challenging. My wife has gone through many non-motor challenges or what I now call invisible Parkinson's disease symptoms. Currently, there is no cure for the disease.

The hardest part of being a care partner to Denise is dealing with having to remain emotionally upbeat even as the journey towards the closing chapters of this disease is relentless. As the news of the number of people living with movement disorders skyrockets, people like Denise and I need grassroot support and compassion now more than ever.

Parkinson & Movement Disorder (PMD) Alliance has been a jewel for people like Denise and I. They walk alongside everyone impacted by the disease, providing reliable resources, empowering education, and listening for understanding. For example, they have provided opportunities for us to work directly with and encourage others in the Parkinson's disease community. This has empowered us by giving us a way to positively impact our community members on this Parkinson's journey. It gives our lives a sense of purpose and meaning.

This Parkinson's Awareness Month, you can make a difference for families like ours across the world by giving to PMD Alliance today:

<https://www.pmdalliance.org/give/>. #pdstoriesunited #PDLooksLikeMe

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## Karen (Person with Parkinson's)

The first thought that raced through my mind when I was diagnosed with Parkinson's disease was that I wanted to prove my neurologist wrong. It was late November 2019. My neurologist had ordered an EMG (electromyography) and during the test my left leg kept shaking. Another neurologist in the practice walked in during the test and said, "Looks like she has dystonia." "Isn't that a country near Russia?" I asked. I had ignored my symptoms even as they accumulated over time. I was a single mom with three adolescent children and I never paid much attention to things that bothered me. I was having increasing difficulty walking; I dragged my left leg and I was unable to swing my left arm.

When the neurologist called around Christmas with the results of my tests, I said to him, "Tell me the good news!" I am an eternal optimist. I was in denial. After an awkward pause, he said, "Karen, there are areas of the brain that produce dopamine that did not light up on your scan." He told me I had Young Onset Parkinson's Disease (YOPD) with dystonia.

In January of 2020, I started carbidopa/levodopa, the gold standard medication for Parkinson's disease. But when my medication wears off, my left hand still wants to contract into what I call the claw. As the medication continued to wear off, my left toes curled under so badly that the tendons tore off the top of my foot and it swelled up like a balloon. Over time I needed more and more medication. My foot would twist inward and my lower leg would twist. Dystonia spread to the entire left side of my body. My autonomic nervous system also became affected. Everything I took for granted like eating started to become difficult. I would be in the middle of making sandwiches for my kids' lunchboxes and I started to have black-outs. I would crawl to the sofa and ask my kids to bring me a glass of water. I would say, "I will be fine in a minute," but I wasn't fine. I was late getting my kids to school and I started having to call other moms to pick up my kids and take them to school.

Living with Young Onset Parkinson's Disease is physically and emotionally challenging, but I choose to begin each day with gratitude and joy. I still have my life, although it has changed. I always think of my father who taught me how to ski. When I fell down he would say, "Brush off the snow, the conditions are great. Let's keep going." My father passed away suddenly in December 2022 but he is in my heart and I still hear his voice telling me to keep going.

Parkinson's for me has been an ever changing journey that at times is isolating. But I made a decision that it's not something to fight: I need to accept and adapt to what the challenges are. The silver lining is the friends I have met locally in my PD support group and around the world in the Parkinson's community. I am overwhelmed with gratitude to have connected to so many special people with Parkinson's who have paved the way ahead of me.

Parkinson & Movement Disorder (PMD) Alliance [pmdalliance.org](https://www.pmdalliance.org) has been a lifeline for people like me. I discovered through their "I Am" poetry project that I could write poetry. The informational sessions are so valuable and truly supportive. They walk alongside everyone impacted by the disease, providing reliable resources, empowering education, understanding, and a compassionate community. This Parkinson's Awareness Month, you can make a difference for people like me across the world by giving to PMD Alliance today: <https://www.pmdalliance.org/give/>. #PDstoriesunited #PDLooksLikeMe