

From Caregiver to Advocate: My Battle Against Parkinson's

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I still vividly remember how lost and confused my family and I felt when we found out that my father was [diagnosed with Parkinson's](#). It was the late 1980s, and information on the disease was quite minimal at that point. My family and I didn't know how to deal with it, and the therapies that were available when he passed are nowhere near the options that we have today.

Learning As We Go

My brother and I tag teamed as co-caregivers for my father, with one taking him to doctor's appointments and paying medical bills while the other did [research on treatments](#) and which medical professionals even existed for people with Parkinson's. We knew we needed to ask questions, but we didn't know the right questions to ask. Even worse, we didn't know that some of his behaviors were in fact symptoms of his disease:

For example, my brother and I often thought that our father was angry with us. As it turned out, it was what some people call the "Parkinson's Mask:" the loss of some control in the face and head muscles creates a blank look that can easily be mistaken for anger. If we had known that he couldn't help his facial expressions, we would have been better-equipped to not take it personally.

Another important misunderstanding in hindsight was [my father's depression](#). For his generation, it was understood that you "tough things out" instead of dealing with your issues. Our lack of

addressing the depression, let alone connecting it to his condition, yielded denial and resentment from him that we didn't know how to properly manage.



Lastly, his pride and stubbornness made it challenging when walking started to become an issue. His refusal to use a cane resulted in some tough falls, to the point where I started padding his elbows and knees, just to ensure that he had some sort of safety protection. It was all about improvisation and going with the flow. We truly were doing the best with what we had at that time.

All of these heartbreaking behaviors, combined with an extreme [lack of information](#), really brought to life the notion that “If you don't deal with Parkinson's, it will deal with you.”

My Immediate Need to Take Action

After such an overwhelming and frustrating experience, I knew there was something I had to do. I needed to [help others obtain the education, support and understanding that I yearned for](#) when my father was battling the disease. So without hesitation, I began working on nights and weekends so I could advocate for Parkinson's research during the weekdays. This gave me the opportunity to spend a great deal of time on Capitol Hill, meeting with members of Congress and eventually contributing to the Morris K. Udall Parkinson's Research Act that was passed in the late 90's. This bill was able to expand and coordinate of research on Parkinson's disease, while improving care and assistance for afflicted individuals and their family caregivers.

But it was the 1994 Parkinson's Action Network Public Policy Forum in Washington, DC, that finally served as my ultimate calling. During that forum, I met Margaret and Martin Tuchman, fellow Parkinson's advocates. While we both had the same goals and vision, the two of them were particularly concerned about the fact that there was amazing Parkinson's research out there – but not enough money. Eager to change that myself, the Tuchmans asked in October of 1999 if I would move from San Francisco to Princeton to start The Parkinson Alliance and address this very concern. I said yes, and the rest is history.

Through my work at The Parkinson Alliance, I have finally been able to take the fear and confusion that I felt as a Parkinson's caregiver and channel it into a strong, flourishing organization that helps provide that very understanding for which I was yearning in the 1980's.

In particular, we have been able to serve as the umbrella organization responsible for the [Parkinson's Unity Walk](#) – the largest single-day grassroots awareness and fundraising event for the Parkinson's community, taking place on Saturday, April 26 in New York City's Central Park.

Making a Difference, One Step at a Time

Since its inception in 1994, one hundred percent of donations from the Unity Walk have gone towards Parkinson's disease research. Every year we host the Walk, the Park becomes electric with energy – buzzing with Parkinson's resources, medical professionals and advocates, all willing to exchange knowledge and share experiences for the greater cause.

In the midst of all the excitement, I always take a moment to look around the Park and realize how unique of an experience the Walk is for so many people – especially for the people with Parkinson's themselves. It's important to remember that going out in public is typically a challenge for people with Parkinson's as they're nervous about people staring when they walk or make sudden movements. But when they see all of the people, who all in some way are working on their disease, they realize they're not alone and that fear of being in public always seems to just melt away, even if just for one April morning in Manhattan.

At the end of the day, the most important thing is to know that resources and support surrounding Parkinson's are exponentially more available than they were back when the disease first came into my life. Organizations like the [Parkinson Alliance](#) and events like the Parkinson's Unity Walk are all readily available to help bring understanding to this all-too-common disease. You are not alone, and together, we will work to find a cure.

Carol Walton is the Chief Executive Officer of The Parkinson Alliance, a nonprofit organization dedicated to raising awareness and funds for Parkinson's disease research. The Parkinson Alliance is the umbrella organization responsible for the Parkinson's Unity Walk – the largest single-day grassroots awareness and fundraising event for the Parkinson's community.