

Caregiver Profile: Julie Beck

A few years ago I used an online match tool that was supposed to pair me with caregiver friends and it came up with zero results. I started to think I was the only caregiver who is younger than 50, a mother of three teenagers and works in a full-time executive position.

“ That changed when I found an online caregiver forum. It was uncanny how much we all had in common. Instant relief took over as I realized I was no longer the only one. ”

My Parkinson's disease (PD) initiation happened after my husband, Dave, was diagnosed with young onset PD (YOPD). It didn't really hit me how serious PD was until the year we bought a house so that we could be closer to my family. Dave was always laid back, yet when it came to purchasing a house he was incredibly adamant that we get this one in particular—the outdated eyesore located across a golf course. We ended up buying the house and remodeling it to meet our needs.

When he was first diagnosed, Dave was prescribed Mirapex. It made him feel good and his tremor went away, but he started to show addictive behavior purchases. I called his doctor to ask if this behavior was indicative of another problem and she casually told me that it was a Mirapex side effect. This was a tough way for me to learn how PD medications affect cognitive function. It explained the house purchase.

Dave was prescribed another medication that did not control his tremors as well as Mirapex. We decided that deep brain stimulation (DBS) surgery was the next best treatment option. Over the next two years he underwent DBS twice, once on each side of the brain. He was still on medication, but the surgery was life changing—allowing him to have a better quality of life for the next six years.

Keeping up with PD is our norm. We regularly go to DBS adjustments, neurologist and psychologist appointments. I directly email his doctors. A successful day is one where my children are happy and no one gets hurt. I'm a caregiver, but I'm also the sole provider for my family. A few years ago I realized I needed to take care of myself, so now I find time to exercise and regularly host my brothers and sisters (my support team) for dinner and celebrations.



Julie celebrates her birthday with her family.

When I need that extra support and comfort I log in to the caregiver forum on social media. Recently, a woman in the forum asked how her life was going to change after her husband was diagnosed with YOPD. I thought about my response for days, which is this: the last 15 years taught me to be ready for change. Cognitive changes happen slowly, so define your new normal as you go. Walk towards change and don't run from it, like I initially did.

The forums helped me feel like I was part of a bigger community. I started looking for other ways to help caregivers. I reached out to the National Parkinson Foundation (NPF), and spoke on a panel at their first Caregiver Summit. Since PD affects everyone differently, I couldn't recommend a universal treatment or instant fix for caregivers, but if telling my story resonated with just one person then I know I made the right decision to speak.

I will continue to be involved with NPF and show them support through Moving Day® Chicago, which I attended for my second time this fall. I know that the money my team raised will continue to benefit the PD community, caregivers included.

Julie Beck is a full-time executive, mother and caregiver.

**For more caregiver resources:
Visit NPF's Caregiver Forum at
www.parkinson.org/forums.
Read Caregiving tips at
www.caremap.parkinson.org.**