

NAVIGATING A PARENT'S PARKINSON'S JOURNEY

Perspectives from Adult Children

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A Parkinson's journey is rarely a solo trek; it is a collaborative effort that reshapes the entire family dynamic. Whether you are navigating this path with a spouse/partner or managing it independently, your adult children often find themselves stepping into a variety of roles to build a stronger net of safety and support. For some, it means being entirely hands-on: driving to appointments, organizing medications/ routines, or simply dropping by for a cup of coffee. For others, separated by distance, borders, or even oceans, it means mastering the delicate art of long-distance care and support: coordinating tricky logistics from a computer screen, scheduling video chats, and managing the quiet ache of being too far away to "be there." For both it is a balance between over-stepping and infringing on independence and ensuring parents are both safe and supported.

We interviewed three adult children about their experiences navigating their parent's diagnoses.

Our first adult child is **Jessica B.** whose family (including parents) are from the Northwest Territories. She helped support her dad (who had Parkinson's but passed away in 2025) and mom (with her own health challenges) while juggling her own family and career.

Next up is **Miles W.**, he and his sister live far away from their parents and face ongoing challenges with how best to support Mom on her Parkinson's journey as well as Dad.

And, finally **Christine L.**, she and her dad (who has Parkinson's) call themselves the "dynamic duo". Christine lives with her dad; and has two brothers who live in different provinces.

With heartfelt honesty, they reflect on the worry, learning curves, shifting roles, and the unexpected moments of grace they have encountered.

Navigating a parent's Parkinson's disease diagnosis brings complex emotional highs and lows for adult children, requiring them to manage changing expectations (including their own) and facing unique challenges like systemic healthcare barriers or the gradual, cumulative impact of the illness. While the initial diagnosis marks the beginning of this collective family journey, the true reality of the disease unfolds over time, gradually reshaping the dynamics between parents and their children.

On Navigating the Parkinson's Journey

Miles shares that there have been, "A lot of highs and lows, but also a lot of community support that has come our way. In the past, it has felt very easy to let the despair take over. But we've also been able to take that despair into a form of action, and catalyst to educate ourselves."

Jessica's experience was shaped heavily by geography and systemic barriers. Living in the Northwest Territories meant that "navigating the healthcare system… was extremely difficult, and accessing proper care required constant advocacy." She explained how isolation and limited access to specialists intensified the emotional and logistical



Jessica B.

challenges. She shared that while these challenges "weren't a burden," they did reshape her priorities and came with a lot of emotional highs and lows.

For **Christine**, "It didn't seem like that big of a deal at first. If I'm being honest there was a bit of relief when he got the diagnosis, some of the things Dad had been experiencing, and I'd been noticing finally made sense."

She noted that the biggest hurdle happened later. "My brothers don't live here, so it's hard for me when they want to weigh in or tell me to stop 'nagging' Dad," she shares. "I know they're just trying to help, but they're not here every day, so they don't see or understand the full picture. It's been tricky to navigate."



Miles W.

How did your role shift as the Parkinson's journey progressed?

The day to day realities of living with a parent with Parkinson's shaped **Christine's** perspective: "As far as Parkinson's goes, my dad didn't have any major issues, so my role changed slowly. I think I let that color my expectations a bit. He's my dad, half of our Dynamic Duo so I didn't want to admit to myself (or him!) things were changing. But I started noticing things he didn't say out loud like missed medications, shifts in how he moved, and harder days in general. Then he had a couple of falls, and I felt the shift. Things were going to have to change to keep him safe and keep me from hovering over him all the time (which he was not a fan of). Those were definitely NOT easy conversations, but we made it through."

At this stage of his mom's journey, **Miles** has become an advocate, researcher and information filter. With so much conflicting data available, finding medically backed facts is critical. "I find myself doing more research and gathering information on their behalf," Miles says. "Helping them sift through all the information and making decisions together has been beneficial."

For **Jessica**, the shift was more encompassing. "Supporting both of my parents became a priority," she shared. "It did reshape how I structured my time, energy, and commitments." Jessica also recognized a broader truth "adult children often become the safety net."

With Parkinson's progression and aging parents in general, caregiving responsibilities evolve over time. They can reshape daily life, adjust priorities, and impact one's emotional bandwidth. The quest to maintain and preserve parents' independence and dignity can also create deeper moments of meaningful connection.

How has this journey shaped you?

The journey fundamentally changed how **Jessica** approaches healthcare and advocacy. She explained, "This experience opened my eyes to the importance of active advocacy. I used to assume that professionals would tell you what to do and when, but that simply isn't how the system works." Over the journey, she learned that Parkinson's and one's healthcare in general requires persistence, involvement, and a willingness to ask questions.

Christine reflected on how living together shaped her understanding of family roles: "It made me realize how fast roles can change in a family. I know that Parkinson's progresses slowly, but it felt like one day he was helping me, and all of the sudden I was helping him. The shift was tough for both of us, he's always been there to help me, and it took time for him to accept my help."

Distance, guilt, and shifting roles played a significant part in **Miles'** journey. He shared that "Both my sister and I have lived apart from our parents for over fifteen years. We felt an immense amount of guilt. We've both learned there are a multitude of ways we can show care and love without being by her side everyday."

Navigating a parent's Parkinson's journey reshapes your perspective, highlighting that while every family's path and support system look different, advocating for your loved ones' care remains essential. As roles and dynamics inevitably shift, adapting to these challenging changes – emotionally, practically, and relationally -- can be difficult. Ultimately, by approaching every hurdle from a place of love and care, you ensure you are always on the right track—even if the road is bumpy or you miss the mark from time to time.

Anything else that resonates with you that you'd like to share with other Adult Children?

Weighing the balance between jumping in or taking a step back an evaluating safety when changes start to take place resonates with **Miles**. He emphasized the importance of respecting a parent's autonomy as their health changes: "Don't infantilize your parents; as long as their safety isn't compromised, their level of independence is their choice." He also reflected on the importance of community: "It's very easy to let our anxiety take over. Surrounding myself with community reminds me that we're not alone and that there is lot that can help manage Parkinson's."



Christine L.

The essential role adult children can play in navigating the healthcare system is what resonates with **Jessica**. She explained that "Having an advocate can make the difference between receiving adequate care and falling through the cracks." Encourages involvement and proactive learning she shares, "Be involved, your parents shouldn't have to manage this alone. Build a network, ask questions, and learn as much as you can." She highlighted the value of unexpected allies, noting that their pharmacist was a vital support. "They helped us understand things no other practitioner explained." She also acknowledged the deep emotional weight and structural challenges of the experience, noting that "the grief begins long before the end and having support matters." This was especially true given the inequities of care in the North; yet, reflecting on the profound meaning of the journey, she added, "While the journey was difficult, it was also meaningful… The experience taught me resilience, patience, and the importance of showing up, even when it's hard."

Two core themes resonate throughout Christine's caregiving journey: the importance of seeking support and the ability to find joy in the present moment amidst ongoing grief. "For our family this was and continues to be uncharted territory", **Christina** explains. "So, I'd say be ok with NOT knowing and asking for help. The best thing we ever did was connect with Parkinson's Association Team. They've been there every step of the way explaining things we didn't know, answering questions and laying out options for Dad and our family. My brothers and I even had a session together where their Team helped us to communicate more effectively with each other so we could better navigate this journey with and for our dad! And, if you live with your parent, take breaks. I didn't at first, and I burned myself out. Just because you're in the same house doesn't mean you have to handle everything yourself." The journey has also taught Christine a valuable lesson, "I learned to pay attention to the small moments, the quiet mornings talking over coffee, the times we laugh and joke like we always have. Those moments make the harder days easier to carry. You end up grieving the changes while still loving the person right in front of you."

Navigating a parent's Parkinson's diagnosis transforms the parent-child dynamic, bringing a complex mix of emotional, physical, and logistical challenges. As adult children step into caregiving or supportive roles, balancing their own lives with the evolving needs of a declining parent requires immense resilience, patience, and self-compassion. Ultimately, this journey is not one that must be walked alone. By seeking out community support, prioritizing their own mental well-being, and focusing on the meaningful moments that remain, adult children can find strength, preserve their bond, and navigate the road ahead with grace.

We want to thank Jessica, Miles and Christine for sharing insight into their journeys navigating Parkinson's. ■