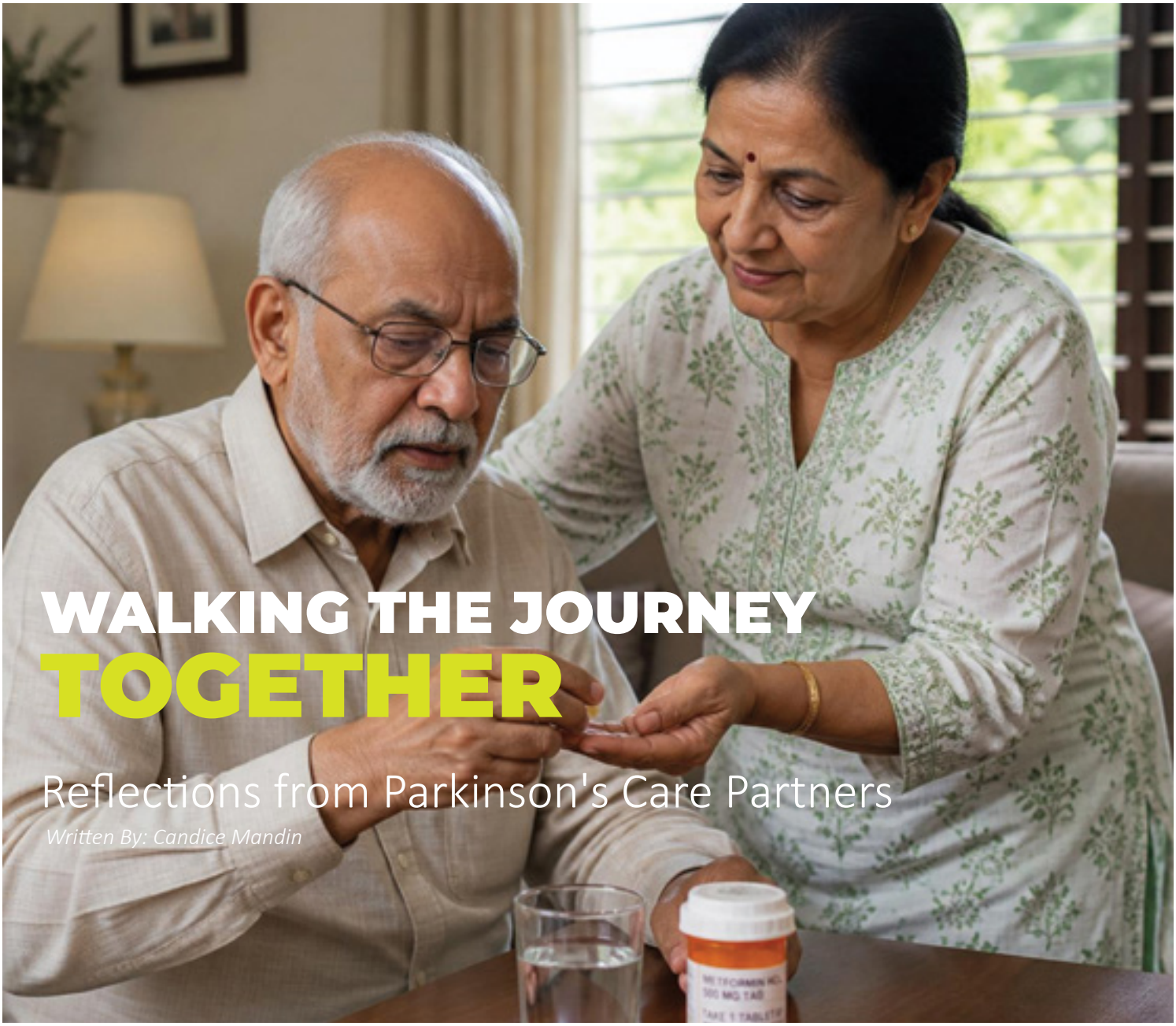


WALKING THE JOURNEY TOGETHER

Reflections from Parkinson's Care Partners

Written By: Candice Mandin

When a loved one is diagnosed with Parkinson disease, life can change in an instant.

Not only for the person receiving the diagnosis, but also for care partners who walk beside them every day. From the shock to the uncertainty of the first symptoms, to the steep learning curve of managing medications, appointments, and changing routines, care partners often carry an invisible emotional weight. The journey begins with a diagnosis that changes not only the future they imagined, but also the rhythm of everyday life. The journey begins with a diagnosis that changes not only the future they imagined, but also the rhythm of everyday life. Every journey with Parkinson disease is deeply personal and no two care partners experience it quite in the same way. For some, Parkinson's enters life during the busy years of careers, raising children and planning for the future through a young onset diagnosis. For others, it arrives later in life, bringing the complex realities of aging with Parkinson's, advanced care, shifting family roles, and increasing physical and emotional demands. Yet across every stage of the disease, care partners are united by the need to adapt, advocate, and find ways to continue living fully in the face of uncertainty. In this article, care partners share the realities behind the diagnosis, the fears, frustrations, unexpected moments of joy and connection, and the lessons learned along the way. Together these voices reveal not only the challenges of caregiving, but also the resilience, compassion and humanity that shape life alongside Parkinson's.

The Day Everything Changed

For many care partners, receiving a Parkinson's diagnosis brought a mixture of emotions. Shock, relief, fear, and uncertainty often arrived all at once. Many questions come flooding in. How will this impact my partner? What will I need to take on? What will this mean for me as a spouse? **Diane M.** recalls feeling "both shocked and relieved." After years spent caring for her mother and mother-in-law, she had believed her caregiving years were behind her. Yet Larry's diagnosis finally explained symptoms that had raised so many questions. For **Cheryl A.**, relief was the overwhelming emotion. "It took four years from the time Vaughn first noticed major symptoms until his diagnosis. It was such a frustrating journey for both of us." After years of tests, therapies, specialists, and uncertainty, finally having an answer brought clarity and a path forward. For others, age added another layer of surprise. When **Allegra M.**'s husband Alex shared his Parkinson's diagnosis on their first date, she recalls. "I was very confused as I had never encountered someone so young with the disease, so I was curious and wanted to know more." What followed was a journey built on understanding, determination, and love. "I trusted my heart and haven't ever looked back. Alex has been and is the love I needed, a great dad and stepdad to our kids, a beacon of determination, unconditional love, and humour. Reminding me to live in the moment."

What Does Living Well Mean?

Living as a care partner to someone with Parkinson's is a journey that often brings unexpected challenges, adjustments, and responsibilities. Along the way, many care partners find themselves balancing their loved one's needs with their own health, relationships, interests, and sense of purpose. Living well as a care partner looks different for everyone. For some, it may be finding moments of joy and connection; for others, it may be maintaining independence, seeking support, or learning to adapt as circumstances change. One theme emerged repeatedly though: caring for yourself is not selfish, it is essential.

For **Navnit G.**, living well means nurturing confidence and finding activities that benefit both partners physically, socially, and emotionally. Diane emphasized the importance of recognizing burnout and making time to relax, laugh, and connect with others. **Rod K.** shared that having his immediate family close, helping with the family bison farm business, is what helps him live well and stay healthy. **Allan N.** reflected on finding peace within yourself: "Living well to myself is finding those moments in time that can give you some peace within yourself, accepting the things you can't change, and enjoying the moments you have together." Allegra shared a powerful reminder that many care partners struggle to embrace: "Taking time for myself and not feeling guilty when I do is sometimes tough, but burnout is real." She stressed the importance of communicating needs, accepting help, and recognizing that both partners have limits.



Allegra & Alex Mackie

The Challenges Along the Way

Every Parkinson's journey is different, but the challenges often evolve over time. What begins as managing appointments or small changes in routine can gradually become navigating physical limitations, emotional strain, shifting relationship roles, and the uncertainty of what comes next. Often, the hardest parts are not only the practical responsibilities but balancing caregiving while trying to care for yourself.

For Navnit, one of the biggest challenges has been the unpredictability of symptoms. She counters this by "listening to the professionals; focus on diet, exercise and socialization; work to support the independence of your loved one." Allan spoke about the difficulty of finding support for an Atypical Parkinson's diagnosis. "My main challenge earlier on was to find some level of support with MSA (Multiple System Atrophy), there are some chat groups but not much in Canada until

we found out that Parkinson Association of Alberta's Atypical group was our support." Rod reflected on the emotional challenge of accepting change. "Learning to accept the changes without getting angry and frustrated with the way our relationship and life had changed. Learning to move forward daily." For Allegra, balancing full-time work, parenting, and caregiving responsibilities created an ongoing challenge familiar to many families. Despite differing circumstances, all shared a common reality: adapting to change while continuing to move forward.

Small Things That Make a Big Difference

Over time, many care partners become experts in finding creative ways to navigate the everyday challenges that come with Parkinson's. Sometimes it is a simple routine, a helpful tool, a communication strategy, or a small adjustment at home that can make daily life feel more manageable. These practical tips and workarounds are often learned through trial and error. They can become invaluable not only for care partners themselves, but for others walking a similar path. We asked care partners to share the best tip, trick, or workaround they have discovered that has helped make daily life a little easier. Rod's advice: "Learn to accept what is." Others focus on routine and structure to help one find time for themselves. Navnit recommends scheduling activities, simplifying daily tasks, and celebrating small achievements even when life is challenging. For Allan, daily exercise has become an important tool for managing stress and maintaining well-being. Allegra shared several practical supports that have helped her family, including a shared digital family calendar, professional counselling, fitness programs, family support, and connecting with Parkinson's community events.

Finding Strength Through Community

One theme surfaced repeatedly throughout these conversations: the value of support and connection.

Care partners described the importance of education, encouragement, and understanding. From support groups to education sessions, to one-on-one individual or family support.

Rod highlighted the value of meeting others facing similar challenges through support groups. Navnit



Cheryl & Vaughn Atkinson

appreciated the emotional support, educational opportunities, and the way families are brought together through support groups, programs and events like the Hope Conference. For Allan, knowing there are knowledgeable people available to help navigate the journey has been invaluable. "Parkinson Association of Alberta is the only organization that has supported us, from the first time we meet with a Client Services Coordinator to participating in classes either online or in person. Knowing you have people within the organization to help you navigate through the journey means more than you can really put in words." Cheryl described having many helpful people as members of their team. "Exercise classes, support groups, education sessions, and other social activities. Step'n Stride is key to demonstrating to our community how we continue to live well with Parkinson's." She noted that online programming has become especially meaningful as mobility challenges have increased, helping them stay connected with others across the province.

Wisdom Gained Along the Way

Perhaps the most meaningful lessons are those learned through experience. Cheryl recalls advice from PAA that continues to guide her: "Parkinson's was definitely going to make us change our expectations about the future, but it needn't force us to let go of what makes us who we are." Rod has learned to focus on one day at a time. Navnit encourages making the best use of each day and celebrating small successes. Allegra shared wisdom passed down through generations from her great grandmother: "Relationships are not 50/50. They're 100/100." And Allan offered a reminder that every care partner needs to hear: "This disease affects everyone individually, but you are not alone."

While every Parkinson's journey is different, these care partners remind us that support, connection, acceptance, and self-care can help us navigate even the most challenging paths. They show that living well is not about avoiding difficulties, it's about finding ways to continue moving forward through them. Together. ■