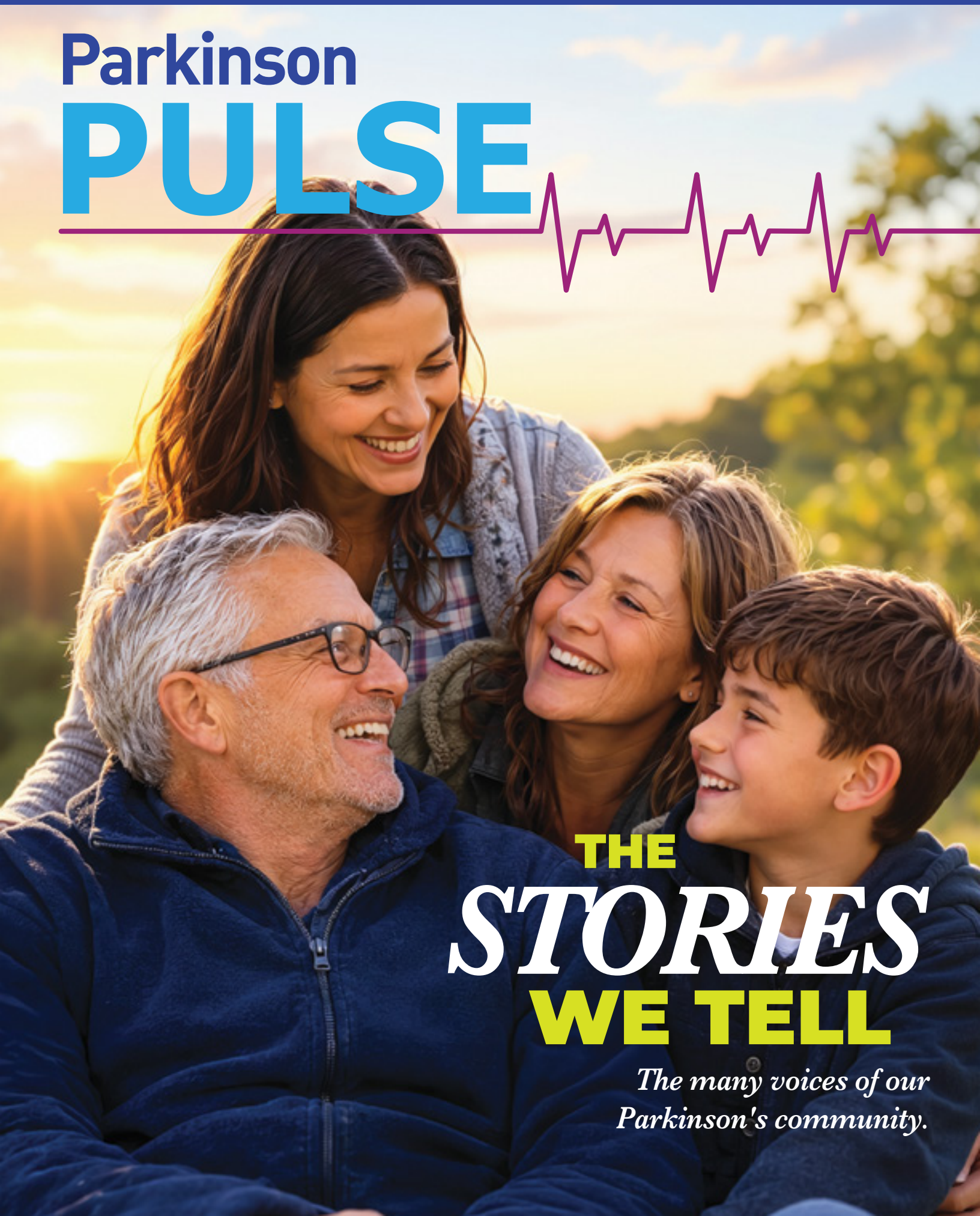
Parkinson Association of Alberta *Quarterly Magazine* Fall 2026

# Parkinson PULSE



## THE STORIES WE TELL

*The many voices of our Parkinson's community.*

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Parkinson Association of Alberta



*Articles and information contained in the Parkinson Pulse are provided solely for the reader's interest.*

*Articles do not necessarily reflect the views of Parkinson Association of Alberta and are NOT intended as medical advice. Please consult your doctor or neurologist in all matters relating to health concerns or medication.*

**Parkinson Association of Alberta empowers individuals and families throughout their Parkinson's journey, responding to each unique need with knowledgeable and compassionate support.**

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CaPRI
Calgary Parkinson Research Initiative

HOTCHKISS BRAIN INSTITUTE

### What is CaPRI?

The Calgary Parkinson's Research Initiative leads Parkinson's research, working toward one shared goal: enhancing the lives of people living with the disease and other movement disorders.

Based at the University of Calgary's Hotchkiss Brain Institute, our team of over 50 expert researchers and staff are advancing early diagnosis, developing new treatments, and creating non-drug therapies that support better quality of life for people with Parkinson's.

### Get Involved

By joining the CaPRI Registry, you can help shape the future of Parkinson's research, support real-world discoveries and help more people get access to new treatments.

Together, we're making progress — one step at a time.

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UNIVERSITY OF CALGARY



# Message from our Executive Director

*Dear friends,*

*Some of the stories we tell are about big moments - a diagnosis, a milestone, a goodbye. Others live in the smallest details: a familiar song, a pet peeve, a private joke. Together, they help us understand one another and remind us how much there is to every person's Parkinson's journey.*

*In this issue, members of our community share experiences that are personal, sometimes difficult, and full of meaning. I am grateful for their willingness to let us into their lives. When someone shares their story, they create an opportunity for another person to think, "I understand that," or perhaps, "I'm not the only one."*

*This year's Step 'n Stride adds another wonderful chapter to our shared story. Its extraordinary success reflects the generosity, energy and commitment of a community that continues to show up for one another. Special thanks to our "Anonymous Donor" who invested not only financially, but by sharing their time and expertise throughout the summer.*

*To everyone who walked, rolled, donated, fundraised, volunteered, sponsored or cheered us on—thank you. Thank you also to our staff and local organizers for the care and effort behind every gathering. Whether you participated in honour of someone, in their memory, or to support a better future for people affected by Parkinson's, you helped make something remarkable possible.*

*The impact carries forward into the support, education and connections that Parkinson Association of Alberta provides throughout the year. You help ensure that people and families have somewhere to turn, people to talk to, and a community who understands.*

*As you read these pages, I hope you find a story that stays with you. And I hope you know that your own story has a place here, to.*

*With gratitude,*
*Lana*



# THE *STORIES* WE TELL

*Written By Brandi La Bonte*



One of the more common requests we get from both those diagnosed and their loved ones is to be connected to someone who is going through EXACTLY what they themselves are going through or approaching a Parkinson's-related issue or concern EXACTLY the way they would. Not only is that sentiment understandable, it's also human nature. Humans (for the most part) are naturally hardwired to seek out others going through the exact same thing because our brains are built to find safety, validation, and clarity in shared experiences. By connecting with someone in our exact circumstance, we use them as a mirror to figure out if our own fears, joys, or reactions are "normal." This specific type of company provides a unique kind of emotional relief that those without the experience (no matter how well-meaning) simply cannot offer. We instinctively look for these "identical" peers because sharing the exact same reality makes us feel more understood, less vulnerable, and less alone in the world. And that can be a beautiful thing; but there is a downside.

If we focus solely on the "exactness" of our unique situation, any slight mismatch can create a dangerous emotional trap that mistakenly convinces us that "no one understands me." This trap can even amplify loneliness. For example, let's say we reach out to a group that seems like they share our struggles, but their specific details or coping styles differ. Our brains may interpret that as a rejection; and we may even think, "If these people don't even understand me, I must truly be alone."

Deep connection relies on finding a shared emotional connection – like the universal feelings of grief, frustration, or guilt – rather than an identical checklist of circumstances. A sum of parts where you weave together your ultimate support system from different people and sources, rather than looking for one perfect match to provide everything. This way if one connection misses the mark, it doesn't break your sense of belonging – it just means you must find that thread somewhere else.

Consider this; if we were to sit in a room with 100 people who had been diagnosed with Parkinson's it is quite likely we'd encounter more differences than we'd encounter similarities. Age at diagnosis, age today, where people live (rural, urban, northern, etc.), symptoms,



how it presents, rate of progression, support circles (or a lack thereof), finances, ethnicities, access to healthcare, transportation, and other vital supports, and even approaches to health and wellness. The Parkinson's experience doesn't fit neatly into a box. It isn't a one-size fits all scenario, and the journey is not an arrow-straight highway. So, what is it then?

If you've been with us for a while you've inevitably heard our staff liken Parkinson disease to tiger stripes or fingerprints; the reference being that the disease is unique to the individual. And while that analogy still holds true, lately we've taken to using a new, updated analogy to include ALL people impacted by Parkinson's. Imagine if you will your life as a thread. This thread is beautiful all on its own; strong and soft, bold and reserved, with an array of colors and textures that tell your story. Absolutely, uniquely you. Now imagine we gather all the threads of people impacted by Parkinson's and weave them together. The result wouldn't be one solid color, nor one, singular repeating pattern; rather a beautifully complex design. A tapestry of strength, compassion, and perseverance alongside guilt, frustration, and sadness. A design that showcases lives lived out loud and moments of quiet reflection. A tapestry that beautifully illustrates tales of hope and fear, holding on and letting go, and love and loss. A tapestry that is a reflection of the stories we tell and the lives we have led thus far. While a diagnosis is given to a single individual, its impact ripples outward, rewriting daily lives, futures, and roles of everyone who surrounds them. To look at Parkinson's through a single lens is to miss the full picture. It is found in the quiet shock of a newly diagnosed grandmother, the disrupted career of a young-onset professional, the fierce devotion of a spouse turned care partner, and the wisdom that comes with the legacy of love and loss felt by a widow. It is carried by adult children navigating the shifting tides of their parents' independence and safety.

We are grateful to those who shared parts of their stories with us for this issue. The stories they tell offer an unfiltered look at the strength, reality, and heart of our community. Their stories, and yours, are woven together into a beautiful tapestry that provides comfort, strength, and a safe space for the Parkinson's community today and tomorrow. ■



# ONE DIAGNOSIS, FOUR JOURNEYS

*Written By Cherlene Magnuson*

*"Don't even think about it. Do it! I always maintain a positive attitude in life and in everything I do."*

*Curtis P.*

Here at Parkinson Association of Alberta, our very first contact with people typically happens in one of two ways: either they or a loved one has been newly diagnosed with Parkinson disease; or they (or a loved one) have had Parkinson's for a while and they are looking for resources and support. Regardless of the reason, we are always happy that they found us. At that first meeting, we often start with the basics to establish a foundation of knowledge and because we all know that "Dr. Google" can lead us down rabbit holes that are not always pleasant or factual. One of the visuals we use to describe Parkinson's is a tiger. The reason we chose that image is simple; no two tigers have the same stripes. Likewise, no two people living with Parkinson's will ever experience the disease in the exact same way. There are too many variables - progression, age, geography, personal approaches to health and wellness, the list goes on and on. So, while a tiger is still a tiger in

the grand scheme of things, each is unique as an individual. Over the past few months, I have had the extreme privilege to speak with several members of our Parkinson's community. Their stories are remarkably different but uniquely bound together.

**Curtis P.** recalls his first symptom being a slight tremor in his left hand. He sought medical advice at once, hoping it was something



*Curtis P.*

else, but when two neurologists independently confirmed Parkinson disease, his fear became a reality. And so, at the age of 49, Curtis was diagnosed with Young Onset Parkinson disease. Like many people diagnosed with Young Onset Parkinson's, the news came as a complete surprise. "Shock, actually," Curtis told me. "I was in denial, to be honest with you. And then I went into a full-blown panic attack. Like, what the hell? I'm too young. So, I didn't take it very well."

What struck me most about Curtis was not his age at diagnosis - but how he responded to it. Today, Curtis is one of the strongest advocates I know for exercise, research participation, and Deep Brain Stimulation (DBS). In fact, he recently shared that he has been selected as one of the first patients in Edmonton to receive Adaptive DBS technology. "The other thing I'm looking forward to, that's on a positive note, is the research," he said. "I participate in every single research study that comes my way."

When I asked what advice, he would give to someone considering DBS surgery, he didn't miss a beat:

"Don't even think about it. Do it! I always maintain a positive attitude in life and in everything I do. I'm just trying to keep myself busy. You don't want to sit and mope around. I think that stress will kill you and sitting around doing nothing will kill you."

Knowing positivity is an excellent skill/tool, but that it is sometimes hard to keep up; I asked Curtis what worried him and how he deals with tough days.

"My biggest worry?... The future, how it's going to play out. I live by myself," he shared. So, he has had to learn to make adjustments and build a network around himself. His son checks in daily. His medical information is programmed into his phone. And he surrounds himself with people through boxing classes, physiotherapy, friendships, fitness programs online and three different online support groups. "That's why I like going out to all these different things. Like boxing. I know if something happens, I'm surrounded by people." For Curtis there are three core truths: 1) community is essential, 2) exercise is equally as important as his medicine, and 3) Parkinson's is something to share, not hide from. "I was trying to hide it a bit, but eventually I embraced it."

**Margaret M.**'s Parkinson's story began in a way few of us could ever imagine. I had asked Margaret: "So how did you manage the news that you had Parkinson's? "That's an interesting question because the day before I was diagnosed with Parkinson's, I had been diagnosed with breast cancer," she said. "So, it didn't really sink in until I would say probably three or four months later, that I had Parkinson's." She was too busy fighting another battle. Months later, the reality of Parkinson's began to settle in. "It was something that was progressive and incurable. Something that I had to manage. I had spent the interim dealing with breast cancer because to my way of thinking, it was more important."

Margaret never hid her diagnosis.



*Margaret M.*

"No. I don't hide things like that. To me, that just causes more anxiety, more stress, more issues going down the road." In fact, she actively invites conversations. "I proudly wear t-shirts with funny or impactful statements/designs that might get people to ask me questions

about it (Parkinson's) so I can educate." One of her favorite t-Shirts says "No Balance" on the front in the same font as a popular show brand logo. When I asked whether people treated her differently after learning about her diagnosis, her answer was immediate. "No. I think it's because I'm so open about it."

Margaret also lives alone, and like other solo individuals living with Parkinson's, she has had to develop systems and develop support networks for herself. "Being solo means, you have a lot more responsibility." She uses multiple alarms. Tracking apps. Daily routines. And, like so many others, she deeply values connection. "The Zoom groups are so important. They are my connections."

I asked Margaret what she thought helped her live her best life on a day-to-day basis, "I'm going to say it's the way I think about and approach each day. That, and Parkinson's Association of Alberta," she shared. "And I mean it because the first thing my neurologist told me to do was call Parkinson's Association of Alberta and become a member, which I did. And then I went back to dealing with the cancer." She explained that the connection to PAA provided pivotal education, support, and community during an incredibly difficult chapter of her life. Margaret also spoke beautifully about finding joy.

"I tend to appreciate things more. Just the little things like being able to watch the clouds or listen to my favorite music. I actually did a silly thing the other day, I went through and figured out what was the number one song at the time of my birthday for every year I've been alive." And of course - she made a playlist.

Perhaps one of the most illuminating insights came when I asked whether she had any fears about the future. "I'm not scared or afraid," she said. "I'm curious and cautious." An honest, vulnerable, and wonderfully human answer. But there was one more gem. Margaret gracefully replied when asked if she had any goals or plans, she wanted to achieve knowing her diagnosis? "No, I think just to enjoy each day as it comes." In her words: "It's the ability to still enjoy doing them." Of course - while wearing a perfectly appropriate t-shirt to start a conversation and bring a smile.

**Dwayne & Shelley L.** have been on the Parkinson's journey for twenty years and help highlight how a diagnosis affects (albeit in different ways) both the person diagnosed and their families. Because Dwayne was only 45 when symptoms first appeared, they were initially told it was not Parkinson's. "And so, we left there thinking, oh, thank goodness it's not Parkinson's because that was our fear. And we kind of just put it out of our heads," Shelley stated. "And then two years later, I started having friends say to me, you know, something's not right with Dwayne. Our kids would come home, and they would say they knew there was something wrong with their dad. So, I promised them we'd go see the doctor again."

When Dwayne was diagnosed at the age of 48, "We were already very familiar with it," Shelley explained. Dwayne's father had also lived with Parkinson's, and they had already seen what the disease could do. "Dwayne took it really tough because he was in denial."

Today, more than twenty years later, Dwayne continues to remain active, engaged, and involved in his community. When I met them, what stood out was their partnership. When I asked what they would tell their younger selves, Shelley offered a unique perspective. "To be honest, I'm going to say it was a blessing." Then she paused. "I'm going to really explain that because a blessing is a pretty broad word. The reason I say that is that you spend your whole life working towards retirement. And we planned that. And when Dwayne got this diagnosis at 48 years old, we knew retirement was now going to look different. And so, we started traveling right away. We honestly have tried to live more for today than we would have otherwise."

I asked both: "So what could you say you're grateful for?" "The progression hasn't been as bad as I thought it was going to be," Dwayne shared. Shelley added, "And I would say we're grateful for family and friends." Their son has spent ten years organizing a Parkinson fundraiser that has raised over half a million dollars. Their children and grandchildren stay central to their lives and why they also live part time in Calgary. "They've been extremely supportive and continue to be."

And what advice would they would offer someone newly diagnosed, Dwayne answered quickly.

"Get active and stay active." Shelley added her own perspective. "It's not an easy journey. Acceptance is the biggest thing. Don't beat yourself up." She spoke about grieving each stage as Parkinson's changes. "Nobody can really understand this disease until you're walking a mile in those shoes." Yet despite the challenges, they continue walking this

journey together, between two provinces - half the time in Saskatoon & the other in Calgary.

If you spend more than five minutes talking with Dulcie W., two things become clear. 1) She tells it like it is, and 2) she will almost certainly make you laugh while doing it. Living in a rural community, Dulcie's Parkinson's journey looks different than urban and suburban dwelling peers. Accessing specialized care means early mornings, long drives, planning around weather, and a different level of preparation that many in the city rarely need to consider. Yet despite those challenges, she approaches life with equal parts of realism and humour.

When I asked if she felt she had lost anything since being diagnosed with Parkinson's, she paused before answering. "I had a better sense of self, of wholeness." An honest and powerful reflection that she acknowledged before shifting toward what she has learned rather than what she has lost. One of those learning moments came through her new DBS journey. Dulcie explained how she expected DBS to work like a “light switch.” Instead, she has learned what so many others eventually discover: All remarkable things take time, healing takes time, programming takes time, and patience is often one of the hardest skills to practice when we are a society that wants instant results.

When I asked her what she wished she had known in those early days after diagnosis, her answer wasn't about medications or exercise; it was about living. She shared (she wished she understood) "How much my life is going to change.” “I think I would have done more in the time that I was, you know, the honeymoon period, when you're doing really well, I would have done more, I think.” Then added: "More travel, more physical stuff while I have the parts that were working. But the other thing I would say to myself is that no, your life isn't over.” Not said with the least bit of regret but rather because Parkinson's has taught her that time is precious. That the things we keep saving for later deserve our attention today.

As our conversation ended, I asked what she would tell someone newly diagnosed. Her answer was simple and beautiful and perhaps my favourite piece of the entire interview: "Your life isn't over." Then she added another piece of her golden wisdom that seems to summarize her entire approach to living with Parkinson's: "You do learn to appreciate what's important to you." Perhaps that is what Dulcie's story is about -- appreciating what matters, laughing whenever possible, and refusing to let Parkinson’s have the final word.

I want to thank everyone who took the time to share their stories, insights and experiences with me. An amazing group of people who (like the Parkinson’s Community as a whole) continue to choose life, purpose, humour, connection, and hope, even when the road ahead is uncertain. None of their journeys look alike, yet every one of them shared something remarkably similar. The story of resilience. ■





# NAVIGATING A PARENT'S PARKINSON'S JOURNEY

## Perspectives from Adult Children

*Written By: Brienne Leclaire*

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. ■






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# THANK YOU TO EVERYONE FOR YOUR INCREDIBLE SUPPORT.

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# WE ARE SO THANKFUL

Our 14th annual Step 'n Stride Walk for Parkinson's was all about showcasing who WE ARE as a community! We've stepped up together and overshot our goal and raised more than **$500,000** for our Parkinson's community!

Across Alberta, more than **1,600** people came together to enjoy a day of fresh air, sunshine, friendship, great food and treats, activities and of course, a chance to walk together to help raise awareness and important funds for those living with, and loving someone with Parkinson disease.

We are once again extremely humbled by the generosity of our participants, volunteers and sponsors, and cannot thank everyone enough.

We look forward to seeing you again next year!



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# THE LITTLE THINGS, AND LIFE AFTER LOSS

*Written By: Lana Tordoff*

Every evening, he made her a cup of tea.

It was a simple gesture, part of the familiar rhythm of their life together. Now, after his death, evenings are the hardest part of her day. The absence of that cup of tea carries the absence of the person who made it.

When I spoke with six widows and two widowers about losing their spouse after living with Parkinson's, it is often these small moments that bring the depth of their loss into focus. A little squeeze around the waist. A song. Something ordinary that happened during the day and would once have been shared.

"I miss the nothingness," one person tells me. "Random little things that happen during the day just don't anymore."

There is humour, too. One participant recalls the "nonstop running of the vacuum," adding, "don't miss that." There is room for an affectionate laugh alongside the sadness. Remembering someone means remembering their habits, their quirks and all the everyday things that made a life together.

Each conversation is different. Yet there are shared experiences: lives changed by a diagnosis, years of adapting, the complexity of saying goodbye, and the question of what comes next.

## A future that changed

For these couples, Parkinson's changes life in ways both large and small.

One couple chose to retire so they could spend as much time together as possible. Their future had changed, and time together became the priority. Their experience is a reminder to make memories while you can.

For others, even interactions with people outside the family can become complicated. Facial masking can mean a spouse is repeatedly asked whether they are angry or sad. People see an expression without understanding the person behind it.

Some participants also describe feeling unsupported by the health care system. One recalls a difficult experience with a physician that made the diagnosis the worst day of their lives. Others speak about the exhaustion of feeling that every step requires a fight. Support for the care partner matters within that experience. Knowing their spouse has someone to turn to can also bring comfort to the person living with Parkinson's.

The diagnosis changes conversations within families, too. Being open and honest with children

becomes more important, and that openness continues after the loss. Hearing children and grandchildren bring up memories of Mom, Dad, Grandma or Grandpa brings happiness. Their loved ones still have a place in family conversation.

## More than one feeling

For some, grief begins long before their spouse dies.

As Parkinson's progresses, there are losses and changes over time. Couples adjust expectations, routines and the ways they spend time together. Some participants feel that this gradual grieving has made the final goodbye less heavy than they might otherwise have expected. That is their experience; it is not everyone's.

After death, sadness can sit alongside relief that their loved one's suffering has ended.

Guilt is also part of several conversations. There are questions about whether more could have been done, about the circumstances of the death, and about what their adult children had experienced. Those questions can remain even after years of devoted care. But there's also an enormous sense of relief that comes from knowing your loved one is no longer suffering.

Then comes another adjustment. For someone whose partner lived in care, being at home alone may already be familiar. But there is a difference between living alone and being alone. Their spouse is no longer somewhere they can visit or call.

The end of caregiving can also leave a loss of purpose. After being needed for so long, what does a day look like when those responsibilities are gone?

## Finding a different way

A common theme is the importance of allowing life to take a new shape.

Several participants speak about choosing new experiences instead of trying to recreate those they had shared with their spouse. Familiar activities and places can feel different now. Giving themselves permission to do things another way helps.

That includes family traditions. Something that has always been done together does not have to continue in exactly the same form. "Used to" isn't your responsibility.

There is permission in that thought: to change a celebration, make a new plan or decide that something no longer works. Memories can remain meaningful without becoming obligations.

Music holds a particular place in remembering. A familiar song can bring a smile one day and overwhelming emotion another. The same memory can feel different depending on the moment.

People trying to help do not always find the right words or actions. Participants speak about remembering that most mean well. At the same time, their experiences show how individual support needs can be.

## Staying connected

The advice they offer is practical: get outside, find a hobby, join a group, volunteer, consider a pet. Reach out when you need to - people often want to help.

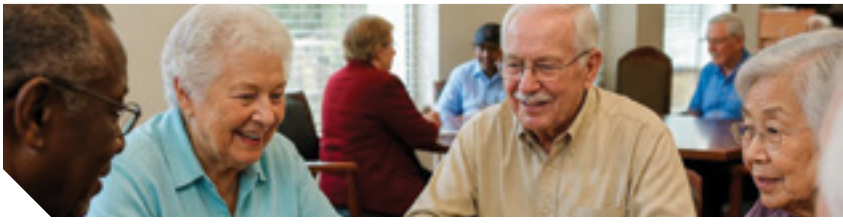
"Don't disappear" is a message that stays with me.

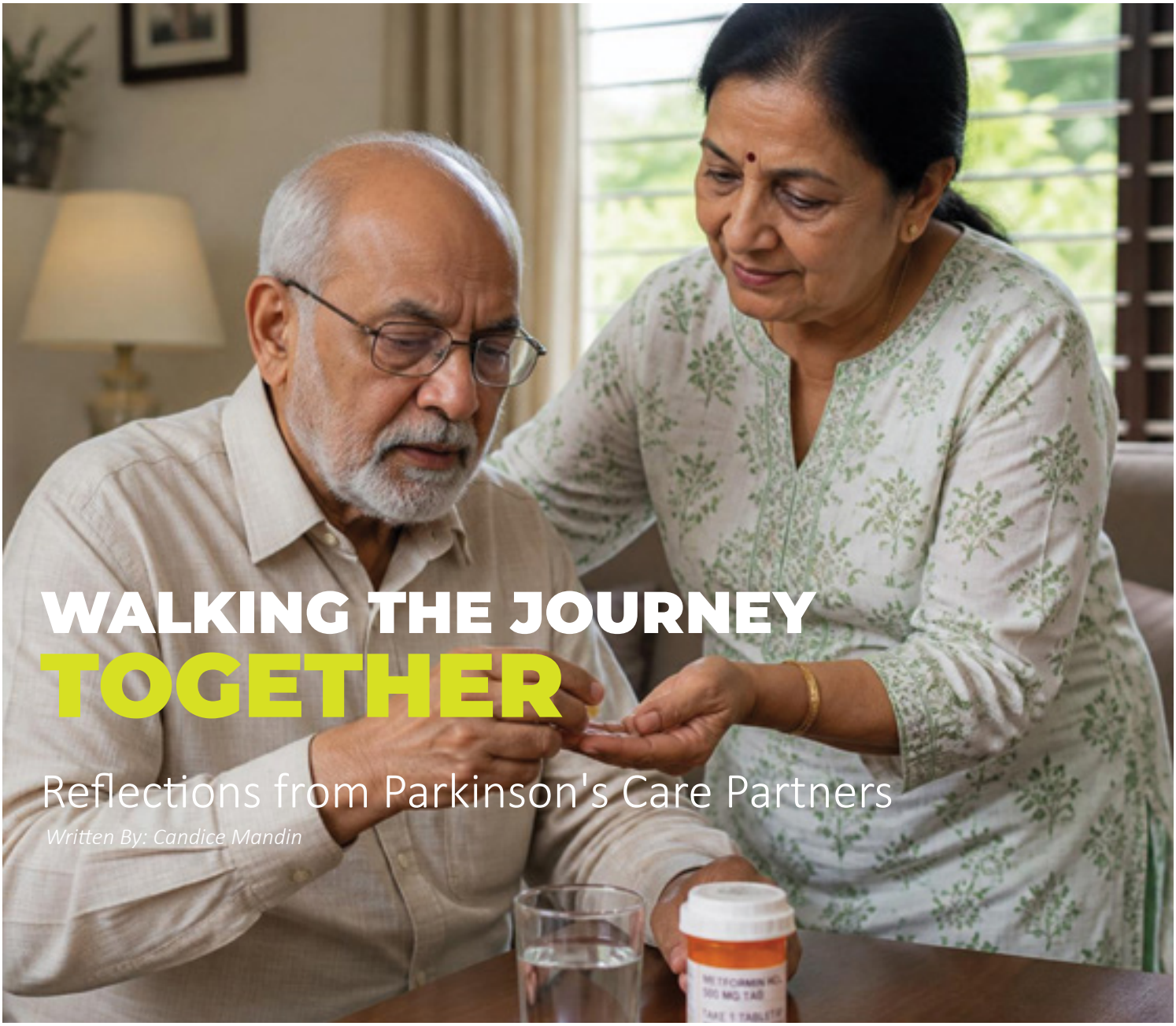
For some, the relationships built in care partner support groups continue naturally after their spouses die. They have already shared so much. Remaining connected as widows and widowers means being with people who understand that history. Others find those connections too painful and choose to step away from the Parkinson's part of their lives. Both choices deserve respect.

What emerges from these conversations is room for different ways of grieving and living. There can be comfort in company, purpose in helping others, or pleasure in trying something new. There can also be difficult evenings and songs that still bring tears.

The invitation from those who share their stories is to live your life and do the things you want to do, with space for the person you miss.

And sometimes, that person is remembered most clearly in the smallest thing: a laugh about the vacuum, a squeeze around the waist, or a cup of tea. ■





# 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. ■



# A JOURNEY THAT REWRITES YOUR DAILY RHYTHM BUT DOESN'T DEFINE YOUR SPIRIT

## Living with Atypical Parkinsonism

Written by: Charlene Heavener

*Brad's advice was simply "LAUGH". Sometimes this is tough but if you look hard enough, you will find something to laugh about!*

For many people diagnosed with an Atypical Parkinsonism, their journey may have begun with a "regular" or idiopathic Parkinson's diagnosis. However, along that journey things likely started to change earlier and faster than they would in "regular" Parkinson's including issues with balance, bladder, speech, swallowing and mobility. As well as limited or no response to Parkinson's medications. When this begins to happen the initial diagnosis may need to be revised to that of Atypical Parkinsonism which includes Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Cortical Basal Degeneration (CBD), and Dementia with Lewy Bodies (DLB). So, just as one is getting used to the idea of having a chronic progressive neurological condition, **WHAM!!** You get hit with a different diagnosis.

I was able to connect with some wonderful folks that are living with an Atypical Parkinsonism diagnosis who openly and honestly shared their insights and experiences.

### When you were told that you had a diagnosis of atypical parkinsonism, what were some of your first thoughts?

David L. shared he was not really surprised with the new diagnosis; he had suspected his Parkinson's was changing too rapidly for it to be regular Parkinson's. **Kerry P.** was somewhat prepared as were **Mike M.** and **Brad D.** due to their own google searches. What most

folks were not prepared for was the lack of information given to them by their health care professionals; most were not given an explanation or any additional information about their new diagnosis. This was very distressing to them as they were not quite sure where to go for information. As the patient, one expects the specialist, doctor, or health care professional to provide information about the medical condition. Some folks were lucky that their family doctor was willing to take the time to learn alongside them.

## How do you approach each day or what do you do to live well every day?

Mike's advice, "Get a good night's sleep, this helps me to do as well as I can the next day." Brad's advice was simply "LAUGH". Sometimes this is tough but if you look hard enough, you will find something to laugh about! **Bruce P.**'s advice, "Enjoy each day as it comes! Tell your wife that you love her and hold her at least once every day. Never take your care partner for granted." Kerry shared, "Do what you can. My mantra has become; I will do as much as I can for as long as I can." **Marilyn N.**'s words of advice, "Keep active, listen to your body and exercise!" David's words of wisdom, "When you are feeling down, just remind yourself that you are not fighting the disease alone, you are part of the PAA (Parkinson Association of Alberta) family now."



*Elaine & Brad*

## Do you have any advice for others with an Atypical Parkinsonism diagnosis?

Bruce was adamant that people, "Join Parkinson Association of Alberta for information, education and support" while Marilyn stated, "I thought I was alone with this rare medical condition, but I have found that there are people with a similar diagnosis and I can relate to them and we support each other". And, in a true testament to the strength of the community each also shared similar advice: "I would tell that person that it is very important to maintain a positive attitude", become educated", an optimistic outlook is helpful for sure; you need to develop a strong attitude of not surrendering to it", "You are not alone on this journey; I am here as a resource, plan ahead. Get the proper safety equipment and use it before you have an accident". Both further added: "Go ahead and live your life, enjoy your life, don't wait until you are feeling better, do what you want to do now."

Throughout my conversations, an underlying theme emerged; and that is to try one's best to approach each day with a positive attitude. It doesn't mean every day is going to be a great one...or even a good one, rather that a positive mindset can help us tackle the day's challenges, bolster confidence and reduce stress. Of course, it's not always an easy task, but as one person put it, "Every day I am grateful for the opportunity to try again."

Thank you to those who shared their insights, the takeaway was as powerful, thoughtful, and resilient as you all are. Living with an Atypical Parkinsonism diagnosis is a journey that rewrites your daily rhythm, but it does not have to define your spirit. While the path ahead holds undeniable challenges, you still hold the power to choose positivity in the spaces between them. Embracing this chapter means giving yourself permission to ask for help, recognizing that leaning on loved ones and your care team is a sign of profound strength, not weakness. And, by anchoring yourself firmly in the present, you can live in the moment and find deep joy in the simple, beautiful constants of today. Tomorrow will take care of itself; for now, breathe, reach out, and claim the peace that exists right here in the present. ■



*Bruce & Pat*

Parkinson Association of Alberta

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**Dr. Corinne Jones**
Speech & Swallowing



**Dr. Satish Raj**
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Calgary December 4
Cochrane December 10
High River/Okotoks November 24

## EDMONTON REGION

Camrose November 17
Edmonton December 11
Fort Saskatchewan November 24
Leduc December 9
Parkland November 24
St Albert December 8
Sherwood Park December 8

## GRANDE PRAIRIE REGION

Grande Prairie December 2

## LLOYDMINSTER REGION

Lloydminster November 26

## LETHBRIDGE REGION

Lethbridge December 10

## RED DEER REGION

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