



I am **ONE** but we are **MANY**

A Solo Discussion on Parkinson's

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The initial diagnosis of Parkinson disease (PD) or a Parkinson's Plus Syndrome can create new challenges and disruptions to your daily living and efforts of future planning. As the disease progresses, these challenges may change or increase, leading to new fears about living with Parkinson's. As Client Services Staff we speak with and get to know a lot of different people across the province. We learn about their challenges and concerns as well as their hopes and joys. We are also able to identify areas where more thought, support and/or education might be needed. One of those recently identified areas has been the unique concerns of managing Parkinson disease solo.

We understand there are always new challenges with the disease, but we also know those managing Parkinson's on their own have additional hurdles to overcome. This is where the idea for this issue of Pulse came from. For my article I sat down to talk with a group of solo members in our Parkinson's community to better understand these difficulties and brainstorm potential solutions to living well with solo PD.

The first challenge identified focused on concerns of isolation and mental health with a chronic condition. And the difficulties that can come with having no partner to brainstorm with or bounce ideas off of, provide support with decision-making processes, or engage in conversation with an understanding of the unique aspects of the disease. Having to face

this unpredictable disease alone and struggling to navigate the uncertainty can leave a person feeling overwhelmed, isolated, lonely, sad, or even angry.

Parkinson Association of Alberta is always here to make sure you never have to walk alone with your disease. We're always just a phone call away with a listening, empathetic ear. We understand the importance of maintaining social connections and prioritizing your mental health. We encourage staying connected to friends, family, and local supports. For example, joining a support group or calling a friend to check in. According to one of our members, being open to accessing supports and engaging in open communication regarding challenging topics can help you realize you're not alone because connections can ease the journey with Parkinson's.

The second area of concern identified for those managing PD solo relates to disease management. From diagnosis through progression, the questions are endless. For those managing Parkinson's independently, the questions predominantly focus on support with decision-making to prepare for the advancing progression of Parkinson's.

Who will monitor my symptoms and side effects throughout the day, months, years? Who will participate in my medical appointments? Who will recognize and express concerns about potential cognitive issues I might not notice or compulsive behaviors resulting from medication? How long will I safely be able to stay in my own home? Who will coordinate my transition to care? Who will plan my funeral?

These questions can be stress or anxiety-inducing for anyone, but often even more so for those managing PD solo. There are things that can be done to mitigate these challenges and/or feelings of anxiety and stress. Although these challenges will have unique responses for each individual, there's a unified agreement that planning for eventualities in advance, building a strong support system and care team to lean on for support can be invaluable.

When thinking about daily disease management, there were many practical concerns expressed by the group, which were met with potential solutions. One of the concerns shared was fluctuating or decreasing energy levels throughout the day leading to difficulties with managing daily living tasks of nutrition through meal prep and cleaning. For nutrition, we discussed using meal services, such as Meals on Wheels or meal kit services (ex. Hello Fresh, Goodfood, etc), using an

air fryer for meals (this was highly recommended!) or trying to prepare meals during your best times of the day according to "on" periods with medications. For cleaning, we discussed cleaning manageable sections of your space when feeling "on" and motivated. We also discussed hiring a cleaning service for periodic deep cleans and personally maintaining with daily/weekly cleaning between.

The secondary practical concern shared was falls and getting up safely after a fall. The challenge with falls and solo PD is lack of direct support available after the fall and potential inability to call an emergency contact afterwards. We discussed the importance of fall detection devices (ex. Telus LivingWell Companion, Phillips Lifeline, etc) or purchasing a smartwatch (ex. Apple, Fitbit, Samsung, Garmin, etc) for a more discreet fall detection device. The final option that could be beneficial is a medical alert bracelet, available in the Aware in Care kit, to inform those in an emergency





situation about your diagnosis. Additionally, we discussed the importance of maintaining physical well-being through exercise and physiotherapy. For example, connecting to community resources such as specialty Parkinson's rehabilitation programs through AHS or community partners offering Parkinson's-friendly programs.

One of the big questions with Parkinson's, especially solo PD, is: how long will I be able to drive? Who will make the decision when it is unsafe to continue driving? How will I manage without a license? These are extremely important questions to consider, as driving is connected to our sense of independence and autonomy. Due to the uniqueness of Parkinson's, decisions about driving will be individual. The decision to retire your license can/will be made with careful self-consideration and input from your healthcare team. If you're feeling unsure about your driving, there are refresher "Brush-Up" courses available through Alberta Motor Association (AMA). If you have decided to retire your license, there are many alternatives available for transportation, including community resources (ex. Access-A-Ride Lethbridge, Access Calgary, Action Bus Red Deer, DATS Edmonton, Lloydminster Handi-Van, GPAT) or independent resources such as an electric bike.

The final area of concern when managing Parkinson's independently is finances. The group expressed concerns about a sole income leading to increased financial concerns and sole medication coverage leading to higher medical costs. We created a brief list, included below, of community and government resources available to support financial concerns:

- » Disability Tax Credit
- » Canada Pension Plan Disability (CPP-D)
- » Assured Income for the Severely Handicapped
- » Alberta Adult Health Benefit
- » Seniors Benefit for Dental, Health, and Optical
- » Alberta Aids to Daily Living

We understand that managing Parkinson disease independently is a challenging task with continual new concerns from progression. We want to emphasize the importance of planning, ahead when able, and reaching out to your support systems to help throughout your journey.