



# Care Partner Advice

## Tips for Caring for Loved Ones with Parkinson's Plus Syndromes

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The role of care partner and/or caregiver is never an easy journey to navigate and often comes without a roadmap for the unpredictable conditions of Parkinson disease or Parkinson's Plus Syndromes. Each day brings a new challenge to manage together but can also bring special moments and memories with loved ones.

When the journey with a Parkinson's Plus Syndrome becomes accelerated due to a more rapid progression and limited response to medications, the role of caregiving becomes essential. The caregivers become the navigators, the advocates, the motivators (sometimes feeling like a constant nag) and the voice for their loved ones, while most importantly still being their spouse. At Parkinson Association of Alberta (PAA), we recognize the essential role of care partners and caregivers and feel honored to continue to support them and their loved ones managing Parkinson's Plus Syndromes.

I had the opportunity of virtually sitting down with James, Ken, and Laurel-Anne, three of our care partners, who shared their knowledge and perspective on caring for loved ones with Parkinson's Plus Syndromes. Together, we've created a list (modified for brevity) of advice and tips for caregivers to keep during their difficult but rewarding journey.

- 1 | Be patient and compassionate with each other
- 2 | Find a balance between addressing your loved one's needs and your own self-care
- 3 | Try to take each day at a time – don't get too far ahead of yourself because there are no roadmaps for progression
- 4 | Maintain open communication throughout the journey between your loved one, yourself, and the health care team
- 5 | Develop communication strategies early (e.g., letterboard or tablet with common phrases) as verbal abilities are likely to decrease with progression



- 14** Complete a Green Sleeve and Personal Directive early to know your loved one's wishes. Don't forget to complete your own Green Sleeve as a caregiver
- 15** Encourage your loved one's independence and empower use of their abilities by allowing them to complete daily living tasks when able or with necessary supports (e.g., adaptive cutlery to safely eat by themselves)
- 16** Use blister packs for medications, which are available by request from the pharmacy

- 6** Be actively involved in your loved one's care, including accompanying them to all medical appointments
- 7** Create and maintain a compassionate healthcare team for your loved one
- 8** Try meeting your loved one's requests in the safest way possible, including different modifications or adaptations, and try managing issues as they arise, regardless of prognosis
- 9** Expect times of total frustration and depression, but also times of deep love and connectedness
- 10** Learn to accept help from others to allow respite for yourself as a caregiver and/or learn to ask for help with specific tasks
- 11** Access resources and supports available through Alberta Health Services (e.g., Home Care services) to take on some day-to-day tasks so you can focus more on your loved one AS a loved one and not a caregiver. This simple act can bring you closer together!



- 17** Practice self-care! Think of your caregiving abilities as a bank; if you continue withdrawing money without replenishing, eventually it will be empty
- 18** Participate in caregiver supports available virtually or locally (e.g., PAA care partner support groups and/or Care Partner Program)

**12** Take lots of pictures!

**13** Write a list of daily living tasks you complete as the caregiver and the required time (e.g., bathing – 20 mins) in preparation for medical assessments



**19** Keep physically close to your loved one (e.g., holding their hand or sitting close by) and spend quality time with them often as you can



**20** Remember that you're managing an extremely challenging situation and doing the best you possibly can for your loved one