



WHY RESEARCH MATTERS

ADVANCED CARE IN PARKINSON'S DISEASE AND RELATED DISORDERS

*Written By: Dr. Karla Cantu-Flores & Dr. Veronica Bruno
ACT-PD – Movement Disorders Program – University of Calgary*

Despite the ongoing scientific efforts dedicated to discovering effective treatments that can decelerate the advancement of Parkinson's disease and atypical Parkinsonian syndromes (PDRD), many individuals worldwide receive the diagnosis and encounter daily challenges associated with these conditions¹. The impact extends not only to the patients themselves but also to their caregivers and families, who must also adapt to life with these diagnoses.

In the advanced stages of PDRD, individuals living with the condition and their caregivers face significant difficulties that significantly affect their lives². These challenges include motor and non-motor problems, such as cognitive changes, hallucinations, frequent falls, and constipation. Planning for care becomes particularly challenging during this stage due to the unpredictable nature of the disease's progression. In addition, while healthcare providers focus on reducing symptom burden, advanced patients and care partners also deal with difficult emotions such as demoralization and grief³.

Recognizing and assisting patients and care partners

throughout this journey is paramount. Regrettably, there has been limited exploration thus far into the specific needs and potential benefits of various interventions for individuals living with advanced PDRD and their care partners. There is a significant need for robust research to understand better and identify the most effective strategies for enhancing patients' and care partners' quality of life.

In a collaborative research study conducted with the University of Alberta, we have recently published an insightful investigation into the healthcare experiences of individuals with PDRD during their final year of life in Alberta. Our findings shed light on these patients' challenges and underscore the urgent need for a comprehensive and compassionate program to support them in their journey.

Our study included a sample size of 1429 individuals diagnosed with Parkinson's disease, Progressive Supranuclear Palsy, Multiple System Atrophy, and Huntington's disease, among others. The results revealed that approximately half of these patients passed away in hospital settings, while two-thirds

experienced hospital stays and emergency room visits during their final year. Less than 10% of these individuals received the palliative and end-of-life care required during this critical period⁴. The absence of Advanced Care Planning conversations among individuals with PDRD is undoubtedly a significant factor contributing to the findings we described. When there is no well-established plan, making decisions during the end-of-life period becomes incredibly challenging. Unfortunately, many individuals with PDRD do not have the opportunity to express their healthcare wishes when confronted with emergencies. This issue further emphasizes the importance of facilitating these conversations to ensure patient preferences and goals are respected and honored during these pivotal moments. By engaging in Advanced Care Planning, we can strive to improve the quality of end-of-life care for individuals with PDRD, empowering them to have their voices heard and their wishes fulfilled.

The findings of our study have brought to light a distinct gap in the care provided to individuals with PDRD, highlighting the urgent need for establishing a comprehensive program in Calgary that specifically addresses advanced care for PDRD patients. In response to these pressing needs, we launched the Advanced Care Team for Parkinson's (ACT-PD) pilot program in October 2022. The primary goal of ACT-PD is to provide earlier access to multidisciplinary advanced care in PDRD while offering personalized support to both patients and their care partners. The ACT-PD team consists of a neurologist, a registered nurse specializing in advanced care, a psychologist, a community liaison, a spiritual care provider, and a research coordinator. Working collaboratively, our team is committed to delivering comprehensive care that caters to the unique needs of patients and caregivers alike.

Through the ACT-PD program, we aim to improve the quality of life for individuals with Parkinson's disease and related disorders, ensuring they receive the holistic support and specialized care they deserve. The ACT-PD program operates on a clinical research model,



with scheduled visits every three months to provide ongoing care and support. Additionally, the program includes follow-up phone calls one and six weeks after each visit, ensuring a clear understanding of the team's recommendations and offering continuous support. To facilitate communication, patients and care partners have direct access to a dedicated phone line and email for any emerging concerns or questions. Currently, the program operates one full day each week at the location of the Movement Disorders program. This schedule allows for dedicated time and resources to be allocated to the comprehensive care and assistance provided to patients and their care partners within the ACT-PD program.

During the two-hour visits, the ACT-PD team assists patients with various concerns. This includes managing their symptoms effectively, establishing personalized goals for their care, addressing emotional well-being, and supporting their care partners. The team strives to offer the best available treatments for physical and non-physical symptoms while aiding patients in planning and providing spiritual support. Mental health assessments are conducted, and counselling sessions are tailored to meet the specific needs of patients and caregivers. Furthermore, the ACT-PD team is crucial in connecting patients with community resources, such as home care services, speech therapy, and financial assistance.

From a research perspective, our primary objective is to demonstrate that this comprehensive and integrated approach to care can significantly enhance the overall experience of patients and care partners, thereby improving their quality of life. Additionally,

Why Research Matters: Advanced Care in Parkinson's disease and Related Disorders

we are committed to ensuring that everyone involved receives education and support regarding advanced care planning, thus ensuring that their wishes are fully expressed and respected.

We aim to provide comprehensive care that addresses the diverse needs of patients and caregivers while also generating valuable research insights to support further advancements in PDRD.

Since its launch, the ACT-PD pilot program has met and exceeded expectations. Initially aiming to recruit 50 participants over two years, the program experienced an overwhelming response within the first six months. In the first six months alone, the ACT-PD team successfully served more than 50 individuals with PDRD and their dedicated care partners.

The overall preliminary results of the intervention showed promising improvements across multiple areas. Participants' satisfaction rates increased, indicating greater contentment and fulfillment. The quality-of-life measurements also showed improvement, suggesting a positive impact on participants' well-being⁵. Care partners experienced a reduced burden, as evidenced by lower Zarit Burden Interview-12 scores⁶. Moreover,

the completion rate of goals of care significantly increased, with 95% of patients actively engaging in educational conversations.

In light of our research study findings and the remarkable accomplishments of the ACT-PD program, it is evident that this holistic approach plays a pivotal role in ensuring a dignified and meaningful end-of-life journey for individuals living with PDRD. Future imperative steps include conversations among healthcare institutions, policymakers, and the community to collaborate and work together. By expanding access to specialized care and implementing comprehensive support systems, we can ensure that individuals with PDRD receive the necessary assistance, comfort, and respect they deserve during the final stages of their disease. Through collective efforts, we can make a profound difference and create a compassionate and inclusive environment that supports the well-being of patients with PDRD and their caregivers in Alberta.

Contact information:

M: actpd@ucalgary.ca

P: (403) 210 7542

References:

- ¹ Wong SL, Gilmour HL, Ramage-Morin PL. *Parkinson's disease: Prevalence, diagnosis and impact*. Ottawa, Ontario: Statistics Canada; 2014.
- ² Lökk, Johan, and Ahmad Delbari. "Clinical aspects of palliative care in advanced Parkinson's disease." *BMC palliative care* 11.1 (2012): 1-8.
- ³ Trachsel, Manuel, and Andreas Maercker. *Lebensende, Sterben und Tod*. Vol. 61. Hogrefe Verlag GmbH & Company KG, 2016.
- ⁴ McKenzie ED, Bruno VA, Fong A, Cai P, Earp M, Camicioli RM, et al. *Health Care Utilization in the last year of life in parkinson disease and other neurodegenerative movement disorders*. *Neurology: Clinical Practice*. 2022;12(6):388–96. doi:10.1212/cpj.000000000200092
- ⁵ Thorgrimsen L, Selwood A, Spector A, et al. *Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale*. *Alzheimer Dis Assoc Disord*. 2003;17(4):201-208.
- ⁶ Zarit SH, Reever KE, Bach-Peterson J. *Relatives of the impaired elderly: correlates of feelings of burden*. *Gerontologist*. 1980;20(6):649-655.



TRUST KAL
WITH YOUR BRAKES

