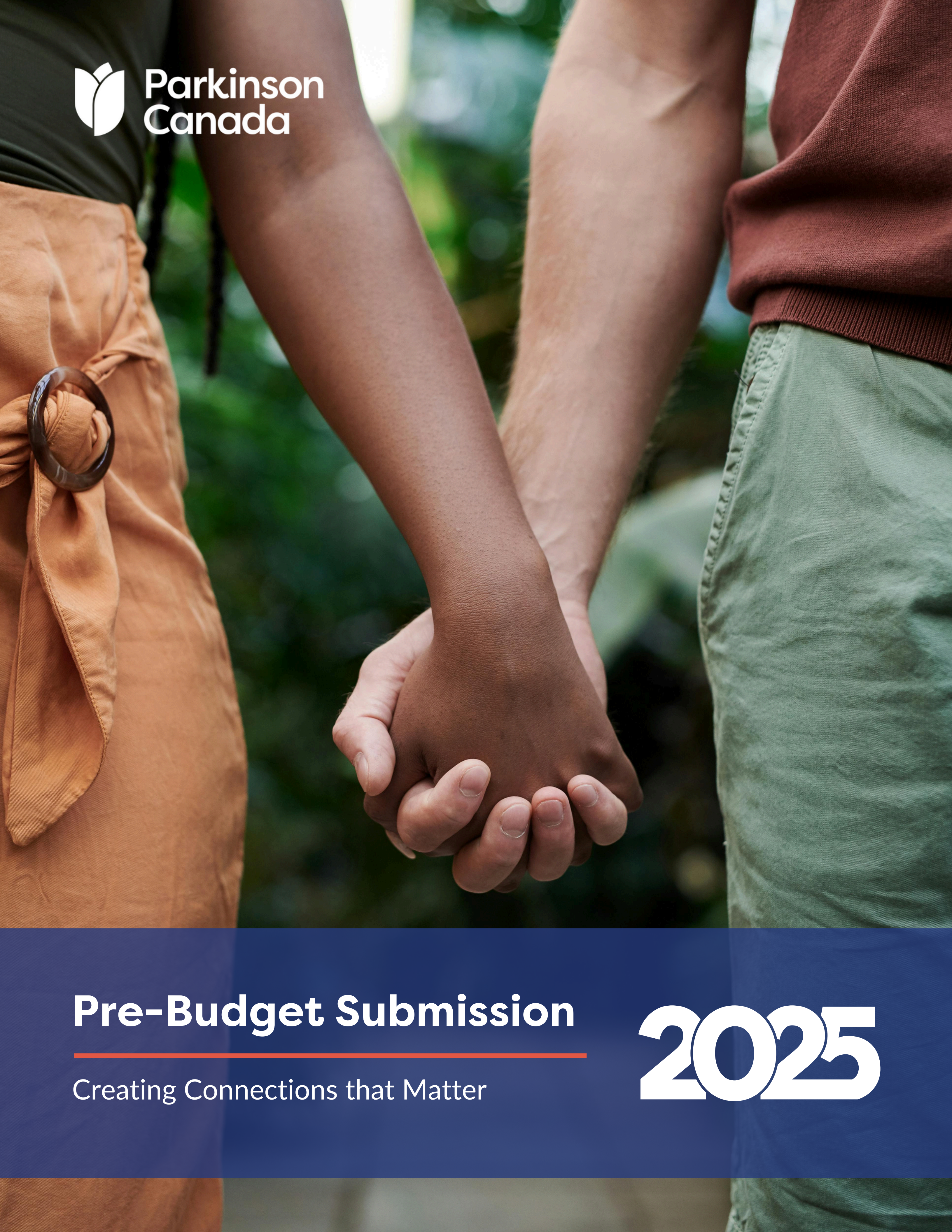
Parkinson Canada



Pre-Budget Submission

Creating Connections that Matter

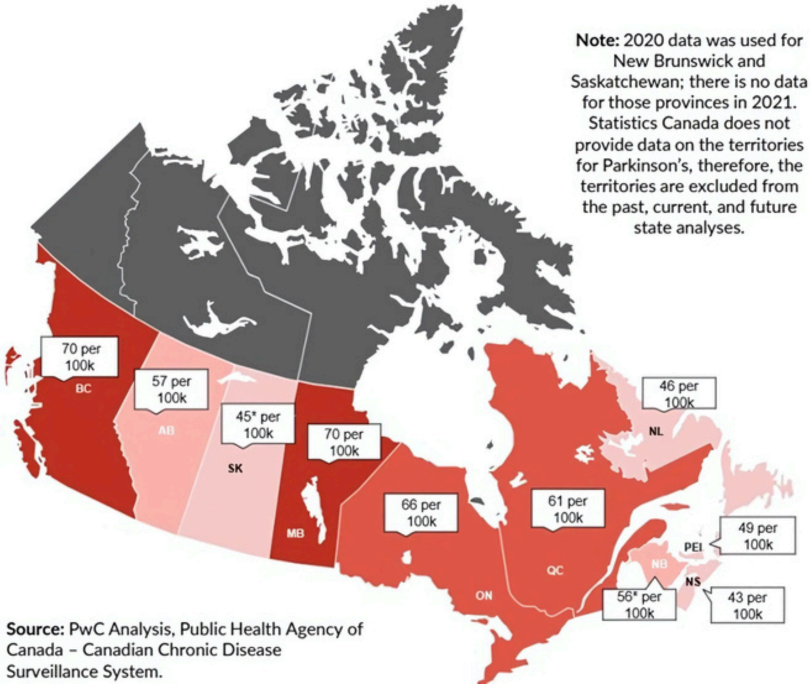
2025

The Growing Reality of Parkinson's in Ontario: Challenges and Practical Solutions

Parkinson Canada is the national organization representing Canadians impacted by Parkinson's. This neurological disorder presents a growing challenge for Ontario, impacting over 48,175 individuals living with it, their caregivers and the province's healthcare system. We believe that living well with Parkinson's is possible, but achieving this vision requires strategic investment and partnership with the Ontario government.

The current reality for those navigating Parkinson's is one of fragmented care, mounting financial burdens amidst a cost-of-living crisis, and a healthcare system that is working hard to keep up with the complex and evolving needs of this growing community.

Figure 4: Parkinson's incidence by province, 2021



Note: 2020 data was used for New Brunswick and Saskatchewan; there is no data for those provinces in 2021. Statistics Canada does not provide data on the territories for Parkinson's, therefore, the territories are excluded from the past, current, and future state analyses.

Source: PwC Analysis, Public Health Agency of Canada – Canadian Chronic Disease Surveillance System.

With both the incidence and prevalence of Parkinson's rising in Ontario —well above the national average at 2% per 100,000 people— we need to work together to implement practical solutions.

Parkinson's costs $3.3 billion annually and this will grow to $4.4 billion within a decade. More than 90% of these costs fall on people with Parkinson's and their care partners.

Parkinson Canada's latest report, The Economic Burden of Parkinson's in Canada, confirms the significant annual cost of Parkinson's nationally: $3.3 billion annually and this will grow to $4.4 billion within a decade. More than 90% of these costs fall on people with Parkinson's and their care partners. Ontario, home to over a third of Canadian's living with Parkinson's, shoulders a significant portion of this financial burden, impacting individual's, families and the healthcare system.

Beyond the financial strain, living with Parkinson's also requires the daily management of both physical and emotional symptoms. There is no cure for Parkinson's or disease modifying therapies. As a progressive condition, there are over 35 symptoms, ranging from tremors and difficulty with mobility, to non-movement symptoms, such as anxiety and depression, sleep issues, cognitive challenges, and dementia. This creates a complex and ever-changing landscape for people with Parkinson's and their families, demanding a flexible and connected support system.

Parkinson's profoundly impacts every facet of life, not only for those diagnosed but also for their families who shoulder the emotional and financial burdens of caregiving. This widespread impact, coupled with the increasing demand for care, underscores the critical need for collaborative solutions.

> ***“Self-management is an integral part of your Parkinson’s. It varies so much hour to hour, so you are not always getting an accurate response. You need to be the quarterback of your healthcare team.” - Doctor living with Parkinson’s, Toronto, ON***

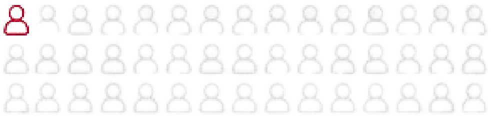
Recognizing Parkinson Canada’s shared goals with the Ontario government to improve access to the right care where and when patients need it, we are pleased to present the following recommendations. We believe that by implementing these recommendations and continuing to build on the important work the province is already doing, we can build a future where Ontarians with Parkinson's can truly live well.

Improve Access to Care

Every person with Parkinson’s experiences their symptoms differently and their treatment plans are designed to focus directly on their specific needs. With the variance in symptoms and treatment plans, access to a comprehensive suite of health care professionals is essential to effectively managing their care. This includes movement disorder specialists, neurologists, geriatricians, general practitioners, physiotherapists, speech-language pathologists, occupational therapists and mental health professionals working collaboratively together.

However, Ontario’s healthcare system is facing increasing pressure, and access to these vital services is becoming more difficult for the growing Parkinson’s community. Our Economic Impact Report reveals that only 74% of Ontarians with Parkinson’s who responded to our survey reported access to a medical doctor. Ontario also performed below the national average in accessing most other allied health professionals, including, mental health professionals, speech and language therapists, and occupational therapists. Of particular concern is the critical shortage of physiotherapists, movement disorder specialists, neurologists and geriatricians across the province.

Evidence demonstrates that access to movement disorder specialists is linked to reduced admissions to long-term care. Specialized care, in general, is also demonstrated to help reduce unnecessary healthcare utilization and costs associated with hospitalizations, emergency department visits and long-term care. [1]



There is **one** Parkinson’s specialist for every **1,379** people with Parkinson's in the province. *Data from 2019

[1] Willis AW, Schootman M, Tran R, Kung N, Evanoff BA, Perlmutter JS, Racette BA. Neurologist-associated reduction in PD-related hospitalizations and health care expenditures. Neurology. 2012

Improving access to specialized care should therefore be the highest priority for treating the Parkinson’s community, while helping the government achieve its goal of enhancing the accessibility and sustainability of the province’s healthcare system. To address this critical gap and ensure Ontarians with Parkinson's receive the timely, specialized care they need, we propose the following recommendation:

1. The Ontario government should improve access to care by strengthening efforts to train, recruit and retain high priority health professionals for the Parkinson’s community, including movement disorder specialists, general neurologists, and geriatricians.

Accessing specialized neurological care, particularly in remote and rural regions of Ontario is a challenge for the Parkinson’s community. Movement disorder clinics, which offer several supports, including specialists with additional training and expertise in Parkinson’s, are primarily located in major urban centres, with limited capacity and far from many rural Ontarians. The result is a significant barrier to timely, Parkinson’s-informed care the community needs.

Movement disorder specialists are tied to urban areas because larger research centres and clinics are there to support them. However, this geographical disparity has significant consequences for people living with Parkinson’s and healthcare system capacity. Notably, people with Parkinson’s in rural areas experience a 35% higher rate of emergency department visits and a 28% higher rate of long-term care admission compared to their urban counterparts.[1]

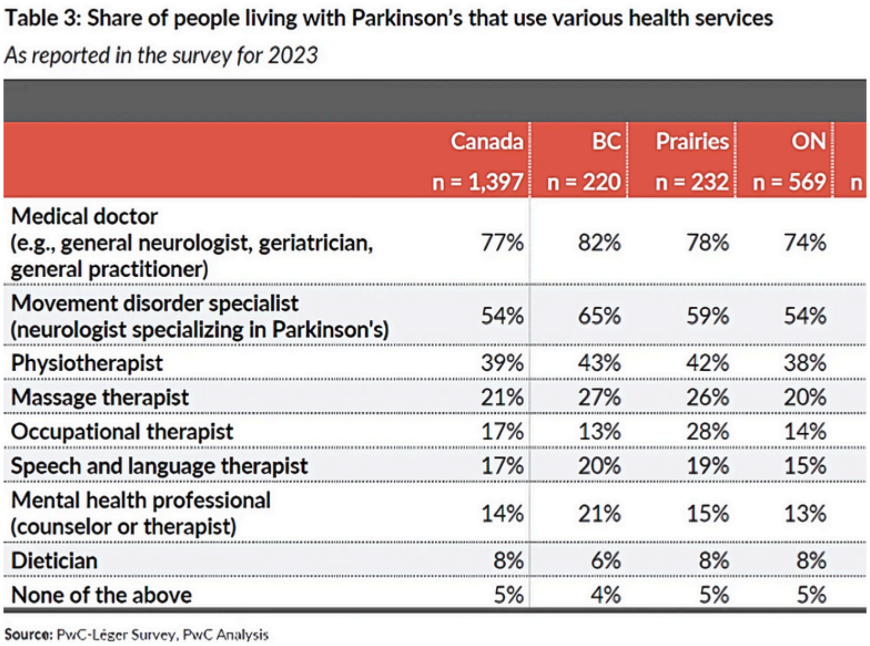


Table 3: Share of people living with Parkinson’s that use various health services

As reported in the survey for 2023

	Canada n = 1,397	BC n = 220	Prairies n = 232	ON n = 569
Medical doctor (e.g., general neurologist, geriatrician, general practitioner)	77%	82%	78%	74%
Movement disorder specialist (neurologist specializing in Parkinson's)	54%	65%	59%	54%
Physiotherapist	39%	43%	42%	38%
Massage therapist	21%	27%	26%	20%
Occupational therapist	17%	13%	28%	14%
Speech and language therapist	17%	20%	19%	15%
Mental health professional (counselor or therapist)	14%	21%	15%	13%
Dietician	8%	6%	8%	8%
None of the above	5%	4%	5%	5%

Source: PwC-Léger Survey, PwC Analysis

Research clearly indicates that access to neurologists, and especially movement disorder specialists, is associated with reduced long-term care placement for people living with Parkinson’s and improved overall well-being.[1] [2]

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[2] Zaman MS, Ghahari S, McColl MA. Barriers to Accessing Healthcare Services for People with Parkinson's Disease: A Scoping Review. J Parkinsons Dis. 2021;11(4):1537-1553. doi: 10.3233/JPD-212735. PMID: 34308913; PMCID: PMC8609702. [1] Willis AW, Schootman M, Tran R, Kung N, Evanoff BA, Perlmutter JS, Racette BA. Neurologist-associated reduction in PD-related hospitalizations and health care expenditures. Neurology. 2012

Practical solutions that help bridge the geographical gap, such as enhanced virtual care options, are an innovative way of ensuring more people with Parkinson's can connect to the specialized care they need, regardless of where they live. To address the geographical disparities in access to specialized Parkinson's care, we propose the following recommendation:

2. The Ontario government should enhance access to neurological care for Ontarians with Parkinson's, particularly in underserved areas, by implementing a two-pronged approach:

- **a. Provide incentives to attract and retain neurologists in underserved areas**
- **b. Expand virtual care options for movement disorder specialists to bridge the gap for people with Parkinson's in rural and remote communities.**

Strengthen Early Diagnosis and Comprehensive Care to Reduce the Burden on the Health System

Early diagnosis of Parkinson's is critical for improving quality of life and reducing the long-term burden on individuals, families and the healthcare system. Right now, knowledge of Parkinson's at the primary care level remains limited, particularly when it comes to recognizing some of the more subtle signs and symptoms that Parkinson's may be present.

> *"It is important to get an early diagnosis so that you can be connected to the right resources and get on the medications you need to prevent any suffering to the quality of one's life." Movement Disorder Specialist, Toronto, ON*

This results in delaying diagnoses for nearly a year on average and sometimes more significantly impacting individuals' mental health and delaying access to essential care, support services and financial assistance.

A delayed diagnosis also prevents people with Parkinson's from receiving access to early interventions that may help to slow progression by preserving functional abilities and helping them to live well.[2] This missed opportunity can have cascading effects, including impacting individuals' ability to work.

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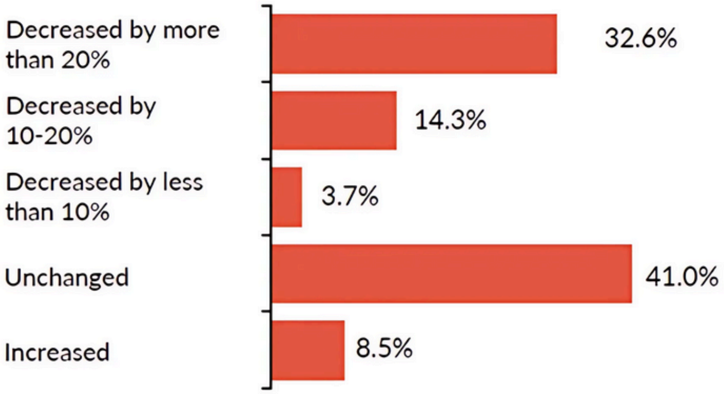
[2] [Footnote reference bottom of pp. 3 of submission]

The economic benefits of early diagnosis are also substantial. In 2022 alone, Parkinson's accounted for $10.2 million in acute care inpatient costs according to our economic burden report. Therefore, a strategy that focuses on early diagnosis and effective symptoms management in the earlier stages could significantly limit overall healthcare expenditures including for medications, increased hospitalizations, and acute care.[1]

Figure 12: Impact on salary for people living with Parkinson's who are currently working*
Average, as reported in the survey, n=136



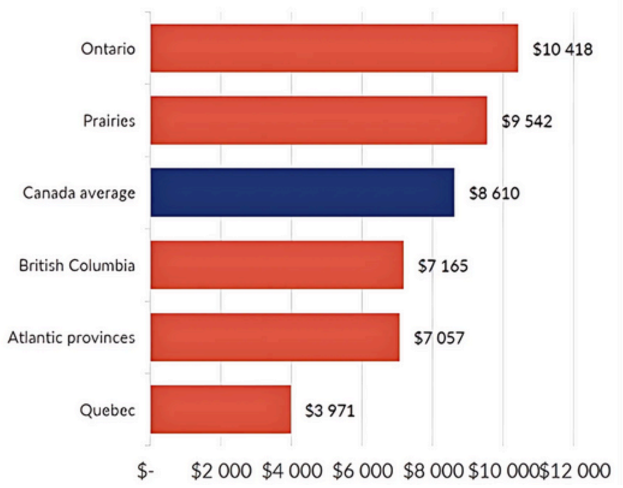
We applaud the Ontario Government's ongoing work to implement the Ontario Health Team Model, particularly in underserved regions, to deliver more coordinated care. However, to maximize the effectiveness of this model, it is critical to ensure that primary care physicians are adequately equipped to diagnose Parkinson's early and connect individuals with the timely, comprehensive care they need. To achieve this, we propose the following recommendation:

3. The Ontario government needs to work with the Ontario College of Family Physicians to enhance primary care education related to Parkinson's that will enable earlier diagnoses and quicker access to comprehensive care.

Enhance Support for Care Partners

Care Partners are the front line of defence for people with Parkinson's and the healthcare system in Ontario. However, existing measures, like the Ontario Caregiver Tax Credit, continue to fall short of meeting their physical, mental and financial needs.

> *"The entire health system is on the backs of care partners. If care partners stopped, the whole system would collapse."*
> *Care partner, ON.*



According to our latest report, the average caregiver in Ontario spends a staggering $10,418 out-of-pocket annually, the highest in Canada- while also receiving the least financial support. This financial burden, coupled with providing an average of 21 hours of weekly care- and up to 30 hours for those with severe Parkinson's leads to 92% of caregivers experiencing income decline due to needing to reduce their own work hours.

[1] [Footnote reference bottom of pp. 2 of submission]

Consequently, according to an Ontario Caregiver Coalition Report, 45% of Ontario caregivers are experiencing hardships, jeopardizing both their well-being and the quality of care they can provide. This can result in both the person with Parkinson's and their care partner requiring hospital care, further burdening the healthcare system.

> ***"I struggle taking care of my husband who has dementia, as I have Parkinson's. There are no support systems for me, even to help me with transportation to medical appointments." - Care partner and person living with Parkinson's, ON.***

A monthly care partner allowance, is a proactive investment that would alleviate financial stress, empower care partners to provide essential support at home, and delay or prevent costly long-term care placements. In fact, a cost-benefit analysis focused on Ontario, shows that for every dollar invested in a care partner allowance, $2.69 is saved on subsidizing long-term care beds. [3] This also aligns with national trends recognizing the vital role and economic benefits of caregiver support, including the new National Caregiver Caucus with federally elected officials and the new Caregiver Benefits in Nova Scotia and Newfoundland and Labrador.

To ensure care partners receive the support they deserve and to create a more sustainable healthcare system, we recommend:

4. The Ontario government should alleviate care partners financial stress by implementing a monthly care partner allowance to ensure that care remains in the home, while reducing stress on Ontario's long-term care system.

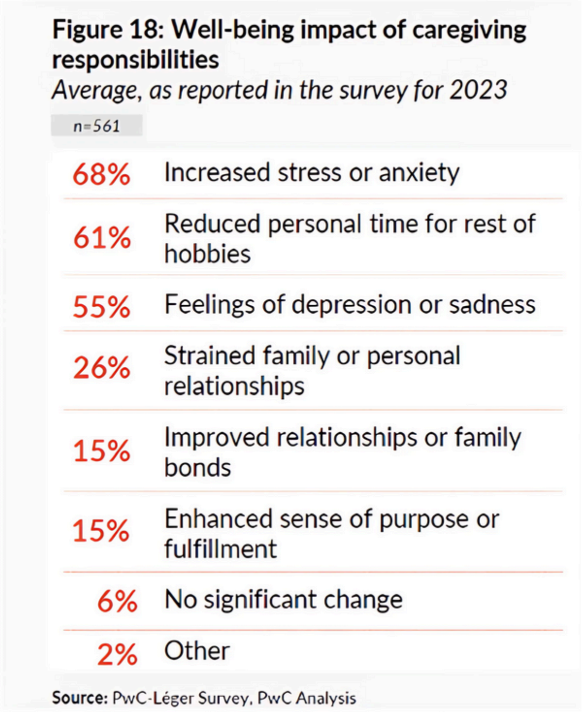


Figure 18: Well-being impact of caregiving responsibilities
Average, as reported in the survey for 2023
n=561

68%	Increased stress or anxiety
61%	Reduced personal time for rest of hobbies
55%	Feelings of depression or sadness
26%	Strained family or personal relationships
15%	Improved relationships or family bonds
15%	Enhanced sense of purpose or fulfillment
6%	No significant change
2%	Other

Source: PwC-Léger Survey, PwC Analysis

The mental and physical health of care partners is a critical yet often overlooked issue. Without access to home or respite care, caregivers experience increased rates of depression and anxiety, both of which are key areas of mental health concern your government is aiming to tackle. [4] This negatively impacts their ability to provide support, contributes to increased levels of absenteeism, and exacerbates existing financial hardships at a time when affordability is already difficult for Ontarians.

[3]La Prairie S, O'Sullivan M, Direct Financial Support to Caregivers: A Cost-Benefit Analysis. Ontario Caregiver Coalition, 2022. https://www.ontariocaregivercoalition.ca/_files/ugd/3e14ad_6570ce52723e4e569abf4d284dc42f30.pdf

[4]Ontario Expanding Mental Health Services in the West. Ontario Newsroom, October 10, 2023. Government of Ontario. https://news.ontario.ca/en/release/1003625/ontario-expanding-mental-health-services-in-the-west.

Respite care is vital for alleviating care partner burden; however, access remains limited. An Ontario Caregiver Coalition survey found only 14% of caregivers had access to respite care support. Furthermore, flexible respite options are largely inaccessible, as eligibility is often evaluated solely based on the person with Parkinson's, rather than the care partner's needs. Insufficient information provided by caseworkers also creates backlogs and extends wait times, leaving care partners feeling isolated and without resources.[5] Connecting caregivers with care coordinators early on is essential to provide timely support before they reach a breaking point.

Recognizing the critical need to address care partner burnout, the Ontario government recently invested in expanded respite care for dementia caregivers, including recreational activities, adult day-programs, and substitute living arrangements to give care partners a much-needed break. Similar measures for Parkinson's caregivers would not only alleviate their burden, but also reduce downstream healthcare costs and the premature need for expensive long-term care. To this end, we recommend:

5. To address caregiver burnout, the Ontario government should expand respite care supports for Parkinson's care partners, mirroring the recent expansion for dementia care partners.

Wrap-up

We would like to thank the Government of Ontario for considering our recommendations. Parkinson Canada looks forward to working with the government to ensure that Ontarians living with Parkinson's and their care partners get the care and support they need to live a vibrant and full life.

If you have questions or would like to learn more about Parkinson's, please reach out to Drake Kindred at drake.kindred@parkinson.ca

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[5] Woodgate RL, Isaak CA, Kipling A, Kirk S. Challenges and recommendations for advancing respite care for families of children and youth with special health care needs: a qualitative exploration. Health Expect. 2024; 27: e13831. doi:10.1111/hex.13831