

Pre-budget submission

in advance of the Fall 2025 Federal Budget



Parkinson Canada Recommendations

Recommendation 1: Listen to people with lived experience of Parkinson's and address known eligibility and accessibility barriers to the Disability Tax Credit to ensure more people with Parkinson's can access this needed tax credit and lessen the negative impact from the economic uncertainty they face.

Recommendation 2: The federal government must work with the provinces and territories to ensure there are adequate numbers of specialists, like neurologists, being trained and entering practice in Canada. We also recommend that this includes removing barriers to the credentialing of internationally trained health care professionals and implementing pan-Canadian licensure for physicians to improve the inter-provincial mobility for health care workers.

Recommendation 3: Invest in Canadian Parkinson's research by enhancing health data collection to support people living with Parkinson's and to better understand best practices for treatment and care.

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Introduction

Canada has one of the highest rates of Parkinson's in the world and some of the highest rates of new cases per year. It is the second most common neurodegenerative disorder after dementia, with more than 110,000 people currently living with Parkinson's in Canada.

There is no known cure for Parkinson's. As a progressive condition, Parkinson's symptoms get worse with new more debilitating symptoms emerging over time. While Parkinson's is typically known for its movement-related symptoms like tremors and difficulty with mobility, non-movement symptoms such as anxiety and depression, sleep issues, cognitive challenges, and dementia can also occur. Not all symptoms of Parkinson's are outwardly visible, and the severity of symptoms can change from day to day and even by the hour.

Parkinson's impacts every facet of a person's life, including their ability to work. Managing Parkinson's requires treatment from a team of physicians, specialists, and allied health professionals, such as physiotherapists, occupational therapists, and speech therapists, often in specialized clinics that can be difficult to access, especially for rural Canadians. As the condition progresses, people with Parkinson's also require extensive care partner support, placing an increased burden on families or close friends to either pay for care or provide it themselves.

Ensuring fair financial assistance & access to disability supports

Listen to people with lived experience and address known eligibility and accessibility barriers to the Disability Tax Credit to ensure more people with Parkinson's can access this needed tax credit and lessen the negative impact from the economic uncertainty we face.

Parkinson's puts a substantial economic burden on people living with the condition, their care partners, and the health care system. In 2024, Parkinson Canada released a report titled **The Economic Burden of Parkinson's in Canada** where we found that Parkinson's costs Canada \$3.3 billion, increasing to \$4.4 billion in 2034. Of these costs, 90% are shouldered by people living with Parkinson's and their care partners. With the increasing economic uncertainty posed by tariffs, the Parkinson's community will likely see this economic burden increase, as the cost of products and medications are impacted.

Our report found that, on average in 2023, people living with Parkinson's paid \$2,612 for home renovation and \$1,628 for medical equipment or aids out-of-pocket.² These are just some of the costs that are incurred by the Parkinson's community to help them live well. Additionally, 53% of people working prior to diagnosis had to stop working or retire earlier than planned due to Parkinson's.³ This leaves many people with Parkinson's, especially those who are forced to leave the workforce years before they otherwise would, in a financially precarious position.

People with Parkinson's and their care partners should have access to the full suite of financial supports available to them which will enable them to live with dignity and independence, but this is not the current reality. Supports such as the Disability Tax Credit (DTC), a credit that by its very definition should help alleviate some of the financial hardships experienced by people with a disability, including Parkinson's, are not accessible. This is, at least in part, due to the insufficiency of the DTC application process to effectively assess the impact of complex and fluctuating symptom presentation such as is characterized by Parkinson's.

Symptoms of Parkinson's can fluctuate in severity day to day and even by the hour. These fluctuations are known as "on" and "off" periods, the latter of which can include symptoms of significant disability resulting from stiffness or freezing, increased intensity of tremors, extreme fatigue, and pain. While Parkinson's is not an episodic condition, the fluctuating nature of the condition means it should be evaluated comparably with an eligibility framework that is responsive to the changing severity and impact that the condition has on a person's ability to complete activities of daily living and participate in work and social life.

In particular, the use of the 90% rule, which is only inclusive of symptoms that are present more than 90% of the time, and the lack of an inclusive definition of disability used by the DTC creates significant barriers in how the impact of Parkinson's is assessed and interpreted for eligibility. The 90% rule makes it nearly impossible for a person living with a chronic condition represented by fluctuating or intermittent symptoms of disability, such as Parkinson's, to qualify. While it has been acknowledged that the 90% rule is a flawed way to measure disability, as of 2024, it is still being used for eligibility in the DTC application form.⁴

With more access to government programs starting to be linked with the DTC, such as the Canada Disability Benefit, our community is concerned that without a rework of the tax credit's eligibility, many people with Parkinson's will be shut out. As noted in Recommendation 416 of the Pre-Budget Consultation in Advance of the 2025 Budget produced in the 44th Parliament, addressing barriers to the DTC is critical in ensuring access to other programs.⁵

There are many stressors associated with managing a chronic, progressive health condition – some of which are unavoidable – but financial stress should not be one of them.

Bolster access to health professionals

The federal government must work with the provinces and territories to ensure there are adequate numbers of specialists, like neurologists, being trained and entering practice in Canada. We also recommend that this includes removing barriers to the credentialing of internationally trained health care professionals and implementing pan-Canadian licensure for physicians to improve the inter-provincial mobility for health care workers.

The economic impact of Parkinson's is substantial and growing every year. There is no question that these impacts are felt by people directly impacted by the condition, including people living with Parkinson's and care partners but by our economy and society as a whole through lost productivity, early retirement, and increased health care costs. We know that when people affected by Parkinson's have access to Parkinson's informed care they need less health system resources, such as hospitals and emergency rooms. A proper treatment plan during the early stages of Parkinson's can also delay the onset of more severe symptoms. It remains incredibly difficult for members of the Parkinson's community to access Parkinson's informed care. By improving access to a proper treatment plan it would not only improve the lives of those affected by Parkinson's and reduce costs to government, but it will also reduce additional strain on the health system.

Care for the growing number of people with Parkinson's requires treatment from a team of health professionals, often in specialized clinics that can be difficult to access, especially for those living in rural areas. Ensuring Canada has the right health care providers to not only diagnose but to help people manage life with Parkinson's is critical. The federal government must work with and encourage the provinces and territories to ensure there are adequate numbers of specialists being trained and entering practice in Canada. We also recommend that this includes removing barriers to the credentialing of internationally trained health care professionals and implementing pan-Canadian licensure for physicians to improve the inter-provincial labour mobility of health care workers.

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Invest in Canadian Parkinson's research

Invest in Canadian Parkinson's research by enhancing health data collection to support those living with Parkinson's and to better understand best practices for treatment and care.

There has been significant progress in learning about Parkinson's over the past several years. These learnings will help us reach earlier diagnoses, improve treatments and better outcomes on individual's quality of life and health. These improvements can help mitigate the most unfavourable impacts of Parkinson's on individuals, health care systems and society, such as lost productivity, early retirement, and increased health care costs. We can't afford to lose this momentum and making investments in Canadian Parkinson's research now is an investment in economic prosperity that will benefit us all moving forward.

One issue that continues to frustrate Parkinson's researchers is the lack of high quality, in-depth data surrounding people living with Parkinson's in Canada that allows researchers to have a complete understanding of people living with Parkinson's in Canada. The Canadian Chronic Disease Surveillance System is only as good as the quality and reliability of the data the provinces provide, which leads to large gaps in accurate modeling and numbers as some provinces do not regularly update their numbers.⁷ Further to this, the information that is provided lacks demographic data, providing only a breakdown by sex. This provides an unclear picture of ethnicity, regional breakdowns, and age-related information. If we as a nation want to truly understand the impacts of Parkinson's and its negative impacts on our health care system and society, then we must invest in better data so we can conduct the best research.

Additionally, there is currently a unique opportunity for countries looking to attract global talent. Decisions made south of the border are already creating uncertainty in the research community, with the potential for significant downstream impacts across all research sectors. These challenges for researchers make clear the importance of bolstering investment in domestic research capacity and demonstrating that Canada will have a stable and robust research ecosystem now and into the future. Having a strong research ecosystem will attract global talent to Canada, which will provide significant returns on investments in research. Now, perhaps more than ever, it is essential for Canada to invest in research.

We strongly encourage the federal government to enhance investments in Canadian Parkinson's research and other funding programs related to Parkinson's care, such as the National Dementia Research Funding program and other brain health research. This investment will not only benefit the health of people living with Parkinson's in Canada and the health care system, but support Canada's future economy as we attract the best and brightest researchers the world has to offer.

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References

- [1] The Economic Burden of Parkinson's in Canada
- [2]https://www.parkinson.ca/wp-content/uploads/FINAL-EN-Economic-burden-of-living-with-PD.pdf
- [3]https://www.parkinson.ca/wp-content/uploads/FINAL-EN-Economic-burden-of-living-with-PD.pdf
- [4]Non-DTC cases
- [5]Pre-Budget Consultation in Advance of the 2025 Budget
- [6] <u>Trends in health service use among persons with Parkinson's disease by rurality: A population-based repeated cross-sectional study | PLOS One</u>
- [7] Canadian Chronic Disease Surveillance System (CCDSS) Canada.ca

About Parkinson Canada

Parkinson Canada is working toward a world where *no one* is limited by Parkinson's. We are committed to raising the voice of people living with Parkinson's and their care partners to advance solutions toward improved care, supports, and quality of life so all people affected by Parkinson's in Canada can live well. We do this by engaging with federal, provincial, and territorial governments to raise awareness of the impact Parkinson's has on the lives of people in Canada as well as through engagement and collaboration with community partners and like-minded organizations.



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