Written Submission for the Pre-Budget Consultations in Advance of the 2024 Federal Budget

By: Parkinson Canada

Recommendations

***Recommendation 1:** The federal government should address known eligibility and accessibility barriers to the Disability Tax Credit to ensure more people with Parkinson's disease are able to access this needed tax credit.*

***Recommendation 2:** The federal government must ensure that as details of the Canada Disability Benefit are developed, the needs and realities of people living with disabilities are central and will deliver meaningful financial support that is accessible for all.*

***Recommendation 3:** The federal government should move forward with its commitment to implement the Canada Pharmacare Act which will address access barriers for the Parkinson's community and articulate a commitment to universality, accessibility, comprehensiveness, portability, and sustainability. Regardless of approach, this must include measures to ensure Canadians do not experience any reductions to their current coverage or increases to deductibles or co-payments.*

***Recommendation 4:** The federal government should work with patient communities, the organizations that represent them, and industry to find novel solutions to address market diversity of medicines and to incentivize pharmaceutical companies to not only launch their products in Canada but to keep them here. This should include measures to implement agile review processes and the incorporation of real-world evidence in evaluation processes.*

> ***Recommendation 4.1:** Government should urgently seek to create incentives and pathways to bring rescue medicines available in other countries to Canada to replace the ones that have been discontinued, closing the current gap in access, and fulfilling the unmet needs of Canadians with Parkinson's disease.*

***Recommendation 5:** The federal government must work with provinces and territories to ensure there are appropriate specialists being trained and entering practice in Canada to support the growing need for more specialized care over time.*

Introduction

Canada has one of the highest rates of Parkinson's disease 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 100,000 Canadians currently living with Parkinson's. Every day 30 people in Canada will be diagnosed, and that number will grow to 50 people per day in less than a decade.

There is no known cure for Parkinson's disease. As a progressive disease, there are over 35 symptoms that impact patients differently and get progressively 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, thinking problems, 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. Though Parkinson's most often affects older adults with an average age of diagnosis at 60, younger people are not immune.

Parkinson's disease impacts every facet of a person's life, including their ability to work - but impacts are not limited to the person with Parkinson's. Caring for a person with Parkinson's requires treatment from a team of physicians, specialists, and allied health professionals, including physiotherapists, occupational therapists, and speech therapists, often in specialized clinics that can be difficult to access. As the disease 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.

Parkinson Canada is the national organization representing Canadians impacted by Parkinson's disease. We believe a full and vibrant life with Parkinson's is still possible, but people with Parkinson's and their care partners need support from all levels of government to fulfill this vision. Together, we can ensure Canadians with Parkinson's and their care partners are supported and empowered to not only manage symptoms but to thrive.

Ensure Tax Credits and Benefits are Accessible and Meaningful

People with Parkinson's and their care partners often face increased expenses as a result of living with a chronic and progressive illness. Reports suggest that for someone living with Parkinson's for 12 years, the median lifespan post-diagnosis, the average lifetime financial cost is on par with that of cancer. The cost of housing, services, equipment, and treatments is a significant economic burden for people with Parkinson's and their families; and inflation has only made affordability even more challenging.

Nearly half of people with Parkinson's report medication as a major financial burden and almost the same number report paying for other treatments, such as physiotherapy, occupational therapy, and speech therapy as a major burden without private benefits or coverage.

There are many stressors associated with and managing a chronic, progressive health condition – some of which are unavoidable – but financial stress should not be one of them. Unfortunately, roughly 50% of people are unable to continue to work five years after diagnosis, increasing to 80% after 10 years.

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.

Canadians with Parkinson's disease and their care partners should have access to the full suite of financial supports available to them and which will enable them to live with dignity, independence, and control – 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.

Disability Tax Credit

Too often, the ability of a person with Parkinson's to work limits, if not completely excludes them from qualifying for the DTC. As a non-refundable tax credit, the DTC's only benefit is to those who currently receive an income. While this is likely an unintended consequence of the current application and review process, it nonetheless represents a clear mismatch between the limits of who qualifies for the DTC and the population it is designed for.

Furthermore, the current application form, including who can complete the form and who evaluates the eligibility of the applicant, is flawed. Parkinson's represents a complex condition whereby people living with the disease fluctuate between "on" and "off" periods day-by-day and even hour-by-hour. It is therefore imperative that those tasked with reporting on the level of a person's disability – and reviewing the eligibility of applicants – have the appropriate knowledge and expertise to do so effectively and fairly and with full consideration of the holistic impacts of their disabilities.

The federal government should expand who can complete the DTC eligibility forms to include any licensed health provider in good standing to ensure forms are completed by those with the best knowledge of the condition and its impacts and who can fairly and more accurately assess the individual's eligibility. Also, the government needs to ensure that when eligibility has been denied, applicants are provided with a clear and specific reason for their denial of eligibility and that appeal processes are timely, transparent, and fair.

The government knows that accessing the DTC is an ongoing issue, which is why it launched the Disability Advisory Committee in 2017. Yet, many of the recommendations of the committee have yet to be implemented.

Increasing stress, including financial stress, leads to greater dependence on other social and healthcare services and supports by increasing the worsening of symptoms. This is bad for people with Parkinson's and their care partners and bad for Canadian systems as a whole. There are simple measures the government can take to ensure people with Parkinson's – and all Canadians living with disability – have the financial support they need to access the services and therapies that will enable them to improve well-being and quality of life.

Canadian Disability Benefit

Parkinson Canada was pleased to see the passing of Bill C-22, Canada Disability Benefit Act. The Benefit has the potential to lift the roughly one million Canadians with disabilities out of poverty. But legislation is just the start. It is critical that as the government undertakes work to establish the details of the benefit, including eligibility, amount, and the application pathway, every effort is made to ensure that Canadians who need it can access and benefit from it. The government also needs to ensure that they meaningfully involve people with lived experience, including organizations that represent them, in the development process. The amount of the benefit needs to be sufficient given the current cost of living, indexed to inflation, and eligibility must not be tied to existing supports, such as the DTC, nor use the same eligibility framework given the existing challenges in eligibility and access.

Make Canada a Leader in Access to Medicines

As there is no cure for Parkinson's disease, access to medicines is critical. To manage their condition and prevent further decline, people with Parkinson's need access to their prescribed medications without financial, geographical, or administrative barriers or the risk of drug shortages or withdrawals. The right treatment plan can significantly improve quality of life, help manage symptoms and disability, and slow the progress of the disease. Medication is one essential component of the right treatment plan for Parkinson's. Unfortunately, people with Parkinson's experience many challenges in accessing necessary medicines.

Pharmacare

People with Parkinson's take multiple medications several times per day and costs for these medicines can range from hundreds to thousands of dollars each month. Additionally, access to medicines and their out-of-pocket costs vary from province to province and drug plan to drug plan, be it public or private.

To decrease the financial burden and create more equitable access to medicines, program principles and funding criteria need to be established by the federal government to support individual provincial and territorial drug plans. These measures could address existing disparities and inequities to ensure a comprehensive range of medicines are available to all Canadians.

Access to Medication

Parkinson's is a progressive disease and as abilities change, such as the loss of a person's ability to swallow, or as symptom management becomes more complex it is critical that people with Parkinson's have access to a variety of treatment options, including a diversity of delivery methods that will enable them to effectively manage their symptoms. Unfortunately, as a comparatively small market, Canada continues to struggle to attract and offer the same diversity of medicines available elsewhere. A relatively small disease population, the Parkinson's community faces additional challenges as low demand prevents industry from launching and keeping Parkinson's medicines in the Canadian market.

Additionally, two critical Parkinson's medications have been discontinued in the Canadian market. Considered "rescue medicines," these are the only two available in Canada of their type. Their discontinuation leaves Canadian patients who rely on these medicines to delay "off" periods when the effectiveness of their regular medication wanes between doses with no alternatives. Taken together, this leaves Canadians with Parkinson's with fewer options for managing their symptoms. Yet, other medications of this type are available in other countries including the US and the UK.

Make Living Well Possible

As noted, care for persons with Parkinson’s requires treatment from a team of physicians, specialists, and allied health professionals, including physiotherapists, occupational therapists, and speech therapists, often in specialized clinics that can be difficult to access.

As the number of people with Parkinson’s grows, ensuring Canada has the right healthcare providers to not only diagnose but help patients manage life with Parkinson’s is critical. The federal government must work with provinces and territories to ensure there are appropriate specialists being trained and entering practice in Canada to support the growing need for more specialized care over time. This is particularly important for addressing the needs of remote and rural communities.

Conclusion

Grounded in the belief that life with Parkinson’s is still possible, Parkinson Canada is committed to ensuring every Canadian with Parkinson’s disease is supported and empowered to thrive. Through tailored programs and services, innovative research and raising the voice of Canadians impacted by Parkinson’s, Parkinson Canada is doing our part – but we cannot do it alone. Government, at all levels, must make Parkinson’s a priority and the recommendations contained here are necessary steps to support Canadians with Parkinson’s.