

Parkinson Canada's Submission to the Pre-Budget Consultation of the Government of Nova Scotia 2025 to 2026 Budget



Introduction:

Parkinson Canada is the national voice for all Canadians impacted by Parkinson's. We work with all levels of government to ensure that a full and vibrant life with Parkinson's is possible.

Canada has one of the highest rates of Parkinson's in the world with more than 110,000 Canadians living with it and some of the highest rates of new cases per year. Currently, there are 2,480 people living with Parkinson's across Nova Scotia. This number may seem small, especially given Nova Scotia's older than average population and the fact that older age is strongly associated with Parkinson's diagnoses. Due to abnormally long wait times for diagnosis in Nova Scotia, we strongly believe that there are a significant number of undiagnosed cases of Parkinson's in the province, which in turn results in under-reported data for the province. To have an accurate picture of Parkinson's in Nova Scotia, more must be done to reduce the wait times and improve access to health care providers with the comfort and knowledge to diagnose Parkinson's.

There is no known cure for Parkinson's. As a progressive condition, there are over 35 symptoms that impact people 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. Though Parkinson's most often affects older adults, younger people are not immune.

Parkinson's impacts every facet of a person's life, including their ability to work. In fact, a <u>recent report from Parkinson Canada</u> focusing on the financial challenges of living with Parkinson's shows that 53% of people who responded and are living with Parkinson's retired earlier than planned due to their Parkinson's diagnosis. Furthermore, their care partners face reduced income from their caregiving duties. Affordability is a real challenge for many Nova Scotians impacted by Parkinson's.

Although there are many challenges that come with living with Parkinson's, our community is hopeful that things can and will be improved. Together, we can ensure Nova Scotians with Parkinson's, and their care partners are supported and empowered to not only manage their symptoms, but to thrive.

Executive Summary:

Nova Scotians living with Parkinson's face several hurdles when accessing the care they need to best manage their symptoms and struggle with making ends meet. From the lack of access to specialists in the province to affordability concerns, people impacted by Parkinson's face barriers in their ability to access the supports and resources they need to live life on their own terms.

Our recommendations are informed by what we have heard from our community in Nova Scotia and some of the most pressing concerns in need of solutions. To address challenges in access to care and affordability, we are calling on the government to create a mobile Movement Disorder clinic for rural residents, ensure that the caregiver benefit does not lose value over time, and continue to work on hiring more Movement Disorder Specialists. If these recommendations are implemented, it would greatly improve the life of Nova Scotians impacted by Parkinson's – along with many others who live with or care for someone living with chronic health conditions - and ensure they receive high-quality care that is accessible and affordable.



Recommendations:

Recommendation 1: Create a mobile Movement Disorder clinic to reduce travel costs and stress for those needing access to Parkinson's informed care in rural areas.

Recommendation 2: Index the Caregiver Benefit amount annually to the Consumer Price Index, so that the value of the benefit isn't eroded over time.

Recommendation 3: Continue to streamline recruitment pathways and reduce barriers for foreign trained specialists, especially Movement Disorder Specialists and other neurologists with expertise in Parkinson's.



Bringing Better Care to Everyone

Parkinson Canada regularly engages with the Nova Scotian Parkinson's community. One of their primary concerns is easy access to Parkinson's informed care. They've told us that unless you live around Halifax, finding a health care professional knowledgeable of movement disorders can be difficult. This is because, according to the <u>Canadian Movement Disorder Society</u>, there are only two clinics specializing in movement disorders in the province and both clinics are in Halifax.

While general neurologists can help people living with Parkinson's, many do not have deep knowledge and expertise on the condition, unlike Movement Disorder Specialists (MDS). We have heard from our community that this lack of expertise means some general neurologists are not able to or do not feel comfortable in giving a clear Parkinson's diagnosis or recommending treatment plans, as noted in our Atlantic Roundtable Report.

From our discussion with our community, we found there is an especially large gap in services for those living with Parkinson's in the Eastern Zone of the Nova Scotia Health Authority. One of our community members from Cape Breton told us that:

"There are three people with Parkinson's on my street, which only has about 20 houses. Parkinson's is prevalent but there has not been any action on it for a long time"- Person living with Parkinson's, Sydney

The drive between the Eastern Zone and Halifax to see a specialist is costly and requires advanced planning. Additionally, our community members from other rural areas of Nova Scotia have told us that they also struggle to access Parkinson's informed care in their own regions and communities. This not only increases the financial burden on individuals to pay for travel required to access care, it places a significant physical burden on people who are already managing a complex health condition. As noted in Parkinson Canada's latest report, The Economic Burden of Parkinson's in Canada, people living with Parkinson's already face significant financial costs due to their condition.

Furthermore, based on an Ontario study on rural health services use by those living with Parkinson's, we know that when people have a harder time accessing Parkinson's informed care, they require emergency rooms more often. It also shows that increased access to neurologist care can improve patient outcomes and reduce potentially unnecessary health system use and cost for persons living with Parkinson's. Not only can a mobile Movement Disorder clinic help bring better care closer to home for rural Nova Scotian impacted by Parkinson's, but it will also help them keep more of their money in their pocket and may reduce the demand on rural hospitals.

Recommendation: Create a mobile Movement Disorder clinic to reduce travel costs and stress for those needing access to Parkinson's informed care in rural areas.

Affordability for Those who Care

There is an ongoing affordability issue across the country; Nova Scotia is no exception. We know that tackling this affordability issue has been a key goal for the Government of Nova Scotia and the government has made progress. One such measure is <u>indexing all Income Assistance</u> to the Consumer Price Index starting January 1, 2025. We believe this is a good measure to ensure that



people who face either significant costs or reduced income do not have their purchasing power eroded over time.

From Parkinson Canada's 2024 report, *The Economic Burden of Parkinson's in Canada*, we know that care partners shoulder significant financial and personal burdens when caring for someone with Parkinson's. For example, 71% of care partners reported having to pay out-of-pocket costs due to their caregiving responsibilities and 92% of care partners saw an income decline after taking on care responsibilities. Of note, care partners in the Atlantic have an average annual cost of \$7,057, clearly demonstrating the affordability challenges care givers face. Higher costs and lower income make for a hard financial blow to any care partner; especially amid the current heightened cost of living felt by all Nova Scotians.

We know that Nova Scotia already provides support to Nova Scotian care partners through the Caregiver Benefit. This program provides much needed support to care partners throughout the province, but as costs continue to rise, the \$400 per month benefit loses its value. To further protect Nova Scotian care partners from heightened costs and affordability challenges, Parkinson Canada believes that indexing the Caregiver Benefit annually to the Consumer Price Index, similarly to how Income Assistance was indexed, will ensure that the value of the benefit is protected from erosion and can keep pace with the rising cost of living.

Recommendation: Index the Caregiver Benefit amount annually to the Consumer Price Index, so that the value of the benefit isn't eroded over time.

Reducing Barriers for Specialists

Parkinson Canada is aware that Health Human Resource recruitment and training is an issue across the country, which is why we appreciate the steps the Nova Scotian government has taken to address this issue by opening additional opportunities and pathways for foreign trained doctors to work in Nova Scotia and helping international medical graduates to become licensed to practice in the province. Reducing barriers for doctors from the <u>United States</u> and from the <u>United Kingdom</u>, <u>Australia</u>, and New Zealand is a crucial first step in addressing on-going staffing shortages. These changes, along with <u>other recruitment efforts</u> from the provincial government, are important for all Nova Scotians.

Unfortunately, the Nova Scotian Parkinson's community still struggles to access Parkinson's informed care. Wait times to get a Parkinson's diagnosis in Nova Scotia have skyrocketed to some of the longest wait times in Canada. We know that for at least one of the two movement disorder clinics in the province, wait times to see one of their specialists remain at 3-4 years. These wait times have a real-world impact on not only those waiting, but on the data we use for Parkinson's research. Our latest report shows a declining incidence rate of Parkinson's from 2011-2021, while more recent data from the <u>Canadian Chronic Disease Surveillance System</u> shows a marginal uptick in incidence from 2021-2023, we believe this overall decrease in incidence is related to the wait times people are experiencing and is causing under-diagnosis and therefore, underreported Parkinson's numbers in Nova Scotia. This hampers the efforts of researchers and risks deprioritizing Parkinson's as a growing issue.



Another key factor that highlights the need for more MDS in Nova Scotia relates to the demand for Long-Term Care usage. According to a study based out of Manitoba, when people living with Parkinson's are treated by specialized care from an MDS, their need for Long-Term Care is reduced. This demonstrates the need for this kind of specialized care. People living with Parkinson's want to stay at home as they age and their symptoms progress, but they need as much support as they can get to do that.

The only way to truly tackle the long wait times and to reduce demand on Long-Term Care lists is to develop a strategy to train and/or hire more MDS's in Nova Scotia. A part of this strategy will require ensuring internationally trained doctors can more easily become licensed to practice in their specialty in the province. Parkinson Canada fully supports the need to ensure that foreign trained doctors are meeting the standards of training and care that Canadians expect from their health care team. However, to meet the current and future demand for health care services, especially specialized services for complex conditions such as Parkinson's, every effort must be made to streamline processes and reduce unnecessary administrative burden to not only make Nova Scotia a desirable place for internationally trained doctors to work, but to enable them to enter practice as quickly as possible.

This is why we are recommending that the Nova Scotia government continue to ramp-up recruitment efforts by streamlining licensing pathways and reducing unnecessary administrative burden for health human resources, with a focus on foreign trained doctors with experience and expertise or who specialize in movement disorders. Engagement with the clinical community in Nova Scotia will be critical to creating solutions that address the unique recruitment challenges that clinics face. We, therefore, strongly encourage the government to consult and engage Nova Scotia clinicians as they develop strategies to ensure Nova Scotians have enough and the right health care practitioners to meet the current and future needs of patients.

Recommendation: Continue to streamline recruitment pathways and reduce barriers for foreign trained specialists, especially Movement Disorder Specialists and other neurologists with expertise in Parkinson's.

We would like to thank the Government of Nova Scotia for considering our recommendations. Parkinson Canada looks forward to working with the government to ensure that people living with Parkinson's in the province get the care they need to live a vibrant and full life. Please reach out to us if you would like to learn more about the Parkinson's community in Nova Scotia and what their concerns are.