# NATIONAL ROUNDTABLE REPORT

Parkinson Canada



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#### **ROUNDTABLE SERIES SUMMARY**

The 2021 Parkinson Canada Roundtable Series consisted of eight regional roundtables, followed by a national session, over the course of three months. This effort brought together more than 150 voices from the Canadian Parkinson's community to gather understanding, insight, and clarity to support Parkinson Canada's advocacy efforts.

The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, we strove for diverse participant representation. People living with Parkinson's, care partners, healthcare professionals, and regional Parkinson's organizations were invited to participate in the roundtables.

Each roundtable was approximately three hours long and included, speakers, large group discussions and smaller breakout conversations. Moderators facilitated the conversation and note-takers were present to accurately capture input and insights from participants. For the purposes of privacy and encouraging an open dialogue, these roundtable sessions were not recorded, and quotations used within this document are anonymously attributed.

This national report summarizes the unique realities faced by members of the Parkinson's community across the country. Following the in-depth discussions from the National Roundtable and building off the eight regional roundtables, we have identified the following key priorities for the Parkinson's community to consider as a way to improve the quality of life for people living with Parkinson's in Canada.

- Identify and address gaps for additional training and knowledge transfer to qualified healthcare providers about Parkinson's, which will allow for earlier diagnosis and treatment of Parkinson's.
- Examine the systemic issues and barriers throughout the healthcare system to determine what steps can be taken to increase the number of healthcare practitioners available to support people with Parkinson's.
- · Advance equitable access to care and improved treatments for all Canadians living with Parkinson's.

These priorities will help provide a roadmap to the organization in developing our future advocacy work in supporting Canadians affected by Parkinson's.



The roundtable series brought together more than 150 voices from the Canadian Parkinson's community



#### INTRODUCTION

#### UNDERSTANDING PARKINSON'S

Parkinson's is a chronic, progressive neurodegenerative disease caused by a loss of dopamineproducing neurons in areas of the brain associated with movement. Individuals with Parkinson's may experience a resting tremor, slowness of movement, muscle rigidity, and balance problems. While Parkinson's is typically thought of as a movement disorder, non-motor symptoms such as anxiety and depression, sleep problems, and difficulty swallowing can also occur as part of the condition. The average age of diagnosis for Parkinson's is 60 years old, but some people are diagnosed prior to 60 and referred to as having early onset Parkinson's.

Currently, there is no cure for Parkinson's or treatments that can stop or slow the progression of the disease. There are only therapies to help manage the symptoms. Most Parkinson's medications work to maintain levels of dopamine in the brain, a neurotransmitter that supports the execution of movement as well as other functions controlled by the brain. The gold standard medication for Parkinson's, levodopa, helps make up for the dopamine lost due to brain cell degeneration. Levodopa was developed in the 1960s. Surgical procedures like deep brain stimulation (DBS) and the insertion of a Duodopa® pump can also be options for people living with Parkinson's.

In addition, the following therapies can help manage Parkinson's symptoms, physical therapy and exercise for mobility, flexibility, and balance; occupational therapy for daily activities; speech therapy to help with voice and swallowing; and mental health services for depression and anxiety.

Every Parkinson's experience is unique, with symptoms and progression varying from person to person. Living with Parkinson's requires a holistic approach to care, which includes all aspects of an individual's life.

#### **KEY PARKINSON'S TERMINOLOGY**

Movement Disorder Specialist (MDS): A neurologist who has completed additional fellowship training in the area of movement disorders.

Wait time: Time an individual must wait to see a healthcare professional.

Care partner: Another term for caregiver.

Multidisciplinary care: This term can have widereaching definitions but for the purposes of this report, it refers to accessing a diverse range of healthcare professionals as part of the management of Parkinson's. Multidisciplinary care models can also involve components such as care coordination, education, and self-management support.

Integrated care: A healthcare model where healthcare professionals from different specialities communicate

and interact in the joint management of care. There can be many different degrees of integration from simply exchanging notes to more in-depth collaboration.

Deep Brain Stimulation (DBS): A neurosurgical procedure where electrodes are implanted deep into the brain and electrical stimulation is delivered through a pacemaker-like device. This electrical stimulation impacts dysfunctioning brain circuits and helps in the management of Parkinson's symptoms.i

**Duodopa®:** A gel mixture of levodopa-carbidopa (Parkinson's medications) administered continuously through a pump into the small intestine. It allows a constant and more consistent amount of levodopa to be present in the body."



#### AN OVERVIEW TO PARKINSON'S IN CANADA

Parkinson's is one of the fastest-growing neurological diseases in the world and Canada has one of the highest prevalence rates compared to other countries.<sup>iii</sup>

It is estimated there are more than 100,000 people in Canada living with Parkinson's in 2021. ivv That number will grow by about 30 people tomorrow and the day after that until we reach 50 new diagnoses per day within 10 years. iv, v

One in five people living in Canada with Parkinson's wait a year or more to receive a formal diagnosis after reporting their symptoms to a medical professional. vi Prolonged wait times to receive diagnosis have serious implications for an individual's quality of life and increase the likelihood for both physical and mental health deterioration.

In 2018, the national wait time average to see a Parkinson's specialist, also known as a Movement Disorder Specialist (MDS), was 11 months with some regions reporting wait times of more than two years. vii It is estimated that there is only one MDS for every 1,500 people living with Parkinson's in the country and most of these specialists are in major urban centres within the provinces, posing a geographical barrier for rural Canadians with Parkinson's.viii

Currently, there are no MDSs in Prince Edward Island or in any of the territories. Furthermore, there are no general neurologists in the territories. People living with Parkinson's in these regions must see travelling neurologists who visit intermittently, or they must attend appointments with clinicians in other provinces.

According to a 2018 IPSOS poll conducted by Parkinson Canada, many Canadians living with Parkinson's pay a portion of healthcare expenses out-of-pocket.vi This includes critical healthcare services like medications and physiotherapy. Furthermore, nearly 75 per cent of survey respondents report paying a portion of exercise class expenses out-of-pocket.vi



# 100,000 &

There are more than 100,000 Canadians living with Parkinson's.



There is approximately **one** Movement Disorder Specialist for every 1,500 people with Parkinson's in the country.

# 308

In 2021, approximately **30** people are diagnosed with Parkinson's every day. Within 10 years, this number is projected to grow to 50 new diagnoses per day.



One in five people living in Canada with Parkinson's wait a year or more to receive a formal diagnosis after reporting their symptoms to a medical professional.



44% of people with Parkinson's pay a portion of expenses out of pocket for physiotherapy.



In 2018, the national wait time average to see a Movement Disorder Specialist was 11 months.



34% of people with Parkinson's pay a portion of expenses out of pocket for medications.



#### **ROUNDTABLE DISCUSSION THEMES**

Three major themes were focused on during the National Roundtable. These themes were extrapolated from conversations that occurred during the regional roundtable series held prior to the National Roundtable.

## HEALTHCARE PROVIDER EDUCATION **FAMILY PHYSICIAN EDUCATION**

During the regional roundtables, we asked participants about their views on diagnosis wait times.

Several participants described circumstances where early symptoms of their Parkinson's were not properly recognized by family physicians, leading to delays in diagnosis. Others encountered difficulty in acquiring referrals to either a neurologist or MDS.

This reality was echoed during the National Roundtable where many individuals said that if their family doctor had been more informed about Parkinson's, it might have allowed for a faster diagnosis.



When participants of the National Roundtable were polled, 89% felt that providing further Parkinson's training to family physicians would accelerate diagnosis.

"I went to see three general doctors over the last year each of them ultimately bows out. They do not seem to want to talk about it. I don't know if they don't know enough about Parkinson's, or what [the reason] is."

- Person with early onset Parkinson's, Winnipeg, Manitoba

As one example from many stories that came out of the conversation, an individual in the group with Parkinson's shared that he felt his family doctor did not have the resources required for diagnosing Parkinson's. He went on to add that had his family doctor been aware of the early signs and symptoms of Parkinson's, it would have helped with receiving a faster diagnosis and referral to a Parkinson's specialist or neurologist.

On the other end of the spectrum, individuals in the group who were quickly referred to an MDS by their general practitioner reported being satisfied with their diagnosis experience.



"Communication between your family doctor and a Parkinson's specialist is essential, and I need to ensure that I help with creating that connection. If it's nonexistent, I need to make sure it happens because it's very important."

- Person with Parkinson's, Broderick, Saskatchewan

A medical professional in the group shared that it is challenging for a family doctor to know a great deal of information on Parkinson's, as there are so many other diseases that they must have extensive knowledge about and be able to treat. There was collective agreement in the group that family physicians are not expected to be experts at diagnosing Parkinson's, but when they have the knowledge to connect individuals to the right resources and get them referred to a neurologist or MDS, it makes for much better health outcomes.

"We can't expect family doctors to know everything about Parkinson's and be an expert, but we need them to know enough to refer."

- Movement Disorder Specialist, Winnipeg, Manitoba

The National Roundtable had several doctors in attendance who confirmed that every medical student does learn about Parkinson's, however the education is insufficient. Parkinson's is usually touched on as part of a larger discussion including other related neurological diseases.

Methods for educating general practitioners were discussed by members of the group and one doctor in attendance suggested the possibility of medical doctors learning more about Parkinson's through Continuing Medical Education (CME) credits. These continuing education courses are mandatory and provide healthcare professionals with up-to-date knowledge and tools that improve their patient care.

Family physicians are pillars of the healthcare system. They are often the first point of contact in the medical system and oversee the holistic health of their patients. Parkinson's is a disease that benefits from multidisciplinary care. It often requires several specialists – neurologists, MDSs, psychiatrists, cardiologists, as well as other healthcare professionals to handle the complex and wide range of symptoms – and family physicians are integral to connecting their patients to the right resources for receiving proper care.

Providing education to support family physicians in recognizing early indicators of Parkinson's and managing the wide-ranging symptoms of Parkinson's would have significant impact on the quality of care for people living with Parkinson's in Canada.



#### ALLIED HEALTHCARE PROFESSIONAL EDUCATION

Parkinson's-specific training for allied healthcare professionals has substantial benefits. Much like the topic of Parkinson's-specific training for general practitioners, we heard from many of the National Roundtable participants about the importance of allied healthcare professionals having proper education in Parkinson's. From one individual who found specialized exercise classes more beneficial, as they targeted multiple symptoms of Parkinson's simultaneously, to a care partner whose father was experiencing weight loss due to Parkinson's and assigned a high-protein diet by an unknowing dietitian who was unaware of the implications it would have on his medication's absorption.



When polled, 100% of National Roundtable attendees agreed that treatments from allied healthcare professionals are more beneficial when those professionals are familiar with Parkinson's.

Each Parkinson's experience is unique, and symptoms will present themselves differently in an individual. Heterogenous by nature, Parkinson's can benefit from a tailored approach in healthcare. There is a tremendous amount of dialogue around the importance of a "team" in treating Parkinson's symptoms. As with general practitioners, allied healthcare professionals play a crucial role and make up much of the "team" that cares for and supports a person with Parkinson's and their family.

During the National Roundtable, many people living with Parkinson's and care partners shared the importance of the holistic care that allied healthcare services provide in the treatment of Parkinson's. Whether it is physiotherapists, speech therapists, occupational therapists, or dieticians – there are a wide array of healthcare and support services that people with Parkinson's require to maintain a quality lifestyle. As critical as these individuals are to the management of Parkinson's, education about the disease is rarely a major component of allied healthcare training.

"More resources are needed. More training is needed. There needs to be basic training in Parkinson's and multidisciplinary approaches. There is basic information about the disease that needs to be shared among healthcare professionals and caregivers, so they have general knowledge about Parkinson's."

- Person with Parkinson's, Trois-Rivières, Quebec



Physiotherapy is one of the most important allied healthcare services required when living with Parkinson's. As time goes on and the disease progresses, the need for physical therapy increases.

A physiotherapist based in Fredericton, New Brunswick, informed the group that her training only had a small portion dedicated to Parkinson's education. She went on to share that a third of her case load involves people with Parkinson's and that she did most of her Parkinson's training after college.

Additionally, there was discussion about providing support for care partners. One individual in the group suggested additional education for social workers for them to offer emotional support and resources to care partners to protect them from burnout. In the 2018 Parkinson Canada IPSOS poll, more than 50 per cent of Parkinson's care partners reported feeling anxious or helpless. vi Whether they are a spouse, family member, or friend – care partners are a foundation of support for people living with Parkinson's.

#### CARE COORDINATION

The subject of care coordination was one of the most popular topics discussed during the roundtable series. There were some who shared that they were fortunate to have a Parkinson's disease specialist nurse as a resource after they or their partner had received a Parkinson's diagnosis and found the support invaluable. Nurses can assist with the coordination of appointments with allied healthcare professionals; connect people living with Parkinson's and their care partners with educational tools, resources, and support group information; as well as check in with individuals through follow-up calls.

Many others throughout the roundtable series had not had the opportunity to work with a nurse care coordinator as part of their medical management but were familiar with the model and fully supported the idea of working to increase the number of nurse care coordinators in clinics across the country.



When polled, 62% of National Roundtable participants said they did not have care coordination available in their region.

Throughout the discussion, a member of the group with early onset Parkinson's shared his experience working with a nurse care coordinator. When he first received his diagnosis, it was the nurse who provided him with information and resources about Parkinson's and connected him with information about local support groups.

His story was echoed by other members in the group who had the opportunity to work with a nurse. A care partner shared with the group how much of a difference it made in her husband's quality of care by having a nurse check in on them and answer their questions. Another participant living with Parkinson's explained how crucial it is after first receiving a diagnosis to have a support in place that will connect you with the right allied healthcare services and give you as much information as possible.



On the other end of the spectrum, there were participants at the National Roundtable who live in more under-serviced, rural parts of the country where neither Parkinson's care coordinator nurses, neurologists or MDSs live and work.

"The lack of facilitated care in our region to support us through this process has been very frustrating. It is so difficult to navigate the care. How do you get proper care when you don't have people advocating for you?"

- Care partner, Yellowknife, Northwest Territories

One of the care partners who participated in the National Roundtable is based in the Northwest Territories and has had many challenges over the past few years with accessing care for her father who has Parkinson's.

In addition to a family physician, community neurologists play an integral role in diagnosis and treatment of Parkinson's for many people. Having a specialized healthcare professional available is important to support people living with Parkinson's as they navigate their journey. Currently, there are no Parkinson's specialists or general neurologists in any of the territories. People living with Parkinson's in these regions must see travelling neurologists who visit intermittently, or they must attend appointments with clinicians in other provinces.

The increase in virtual medical care since the COVID-19 pandemic began is an unexpected benefit for the care partner and her family. She went on to share that through telehealth she managed to secure an appointment for her father with a neurologist in Calgary, Alberta and during that meeting they learned about MDSs. They were able to get an appointment with a MDS and recently returned from Calgary where her father had the Duodopa® surgery.

The care partner shared with the group that about a week after the surgery a nurse called to check in on her father. The nurse gave them pertinent information on other medications, discussed physiotherapy options, speech therapy options, diet considerations, etc., and gave them the comfort of knowing there was someone there to offer them support.

"This was the first time in our eight-year Parkinson's journey that someone contacted us to check in and provide information and answer our questions. This was a very emotional experience that brought me to tears and reinforced the importance of having proper nurse care."

- Care partner, Yellowknife, Northwest Territories



The topic of patient education became the next focus of conversation. Members in the group discussed the importance of giving newly diagnosed individuals as much information as possible about Parkinson's, as well as information on what resources are available.

Certain members in the group said they received a pamphlet of information after being diagnosed. There was no other information provided by their doctor and no follow-up. These individuals had to conduct their own research about the additional resources available to them.

A member of the group who is a Parkinson's specialist mentioned how the number of individuals with Parkinson's seems to be going up in his region and they have had to hire more neurologists at his clinic. With only one nurse on staff, the workload is rapidly growing. He feels it would be helpful to have funding in place to hire more nurses to support the growing number of individuals with Parkinson's and ensure every person living with Parkinson's is connected to timely educational information

"Post-diagnosis information is critical. People need to be educated, including family and friends who are caregivers. They are part of the journey too."

- Person with Parkinson's, Winnipeg, Manitoba

As the number of people living with Parkinson's continues to rise in Canada, increasing the number of nurses who can provide care coordination and connect people with Parkinson's to information and resources would be highly beneficial.



#### ACCESS TO MOVEMENT DISORDER SPECIALISTS

Throughout the roundtable series, we heard about challenges participants experienced trying to access a MDS. There were some participants in the group who expressed frustration with how long it takes to get into a movement disorders clinic due to the small number of them that operate in their region. Others shared that when their family physician referred them to a general neurologist, the neurologist was unable to make the Parkinson's diagnosis; it was not until they had met with a MDS that they finally received a diagnosis.



When people living with Parkinson's and care partners in the group were polled, 82% responded that additional training of Movement Disorder Specialists is necessary for the medical management of Parkinson's.



When medical professionals in the group were polled, 83% responded that the additional training of Movement Disorder Specialists is necessary for the medical management of Parkinson's.

"We need more than one approach to get more Movement Disorder Specialists, especially with government cutbacks and healthcare professionals leaving. The government needs to play a role in keeping them here in Canada."

- Community organization representative, Calgary, Alberta

The final portion of the National Roundtable began with a presentation from a MDS based in British Columbia on the process of becoming a MDS and the barriers for keeping them in Canada.

To become a MDS in Canada, a doctor completes an undergraduate degree (and sometimes a master's or PhD as well) followed by three to four years of medical school and a post-medical graduate education also known as residency. This is a cumulative 13 to 17 years of post-secondary education.

Upon completing residency, a neurologist can then get their license from the College of Physicians and Surgeons in their province and start practising as a general neurologist, or they can do several more years of fellowship training.

In fellowship training, a neurologist can pursue sub-specialty training in several different areas, with movement disorders being one of them.



A MDS will complete one to two years of fellowship training at a movement disorders clinic, which includes the following: exposure to rare conditions and unusual presentations of common disorders involving involuntary movements, experience with advanced treatments for Parkinson's, experience working in a coordinated manner with an allied healthcare team, dedicated movement disorders educational seminars (aka "rounds"), training in deep brain stimulation and Duodopa® pump programming, and clinical research.

After fellowship training, a MDS will either be hired by the clinic where they trained, or by another movement disorders clinic in Canada. Alternatively, they will work in an under-serviced area of the country and try to establish a new movement disorders clinic there.

So, what is the barrier to attracting more neurologists to movement disorders fellowship training? The answer is funding. In addition to a lack of funding, the number of medical students admitted to a residency program is low. In 2021 there were only 2,083 funded residency positions in Canada and only 49 of these positions were designated for neurology, ix Only a select number of these residents will seek out a movement disorders fellowship, and presently there is no funding for movement disorders fellowship training provided through the medical education system. This means any neurologists interested in fellowship training must independently seek out their own funding.

"Academic fellows at institutions must be fully funded to participate in fellowship training. Currently, there are only two partially funded MDS fellowship positions in Canada, both of which are funded by Parkinson Canada."

- Movement Disorder Specialist, Surrey, British Columbia

To fulfill the funding requirements fellows must find a source of private funding, which is often provided by pharmaceutical companies. The lack of neurology residency positions and funding for movement disorders fellowships are significant deterrents that prevent doctors from seeking out the much-needed skills in this area.

"My experience with Parkinson's is quite new, but the topic of losing highly-trained specialists to the U.S. is close to my heart. I just lost my neurosurgeon, which is so hard for me as I [also] have epilepsy. I don't blame my neurosurgeon because he felt that he couldn't make the investment into Canada, because an investment wasn't made into him."

- Person with Parkinson's, Winnipeg, Manitoba



Another barrier that was mentioned is the competitive edge that the United States currently has over Canada in terms of the compensation packages they offer as recruitment tactics. Large salaries, signing bonuses, benefits and substantial paid vacations are some of the incentives that are offered to Canadian-trained neurologists and MDSs.

More MDSs in Canada will not happen without long-term investment. In the absence of more funding, neurologists will either gravitate to other sub-specialities in their fellowship (neuromuscular, stroke, epilepsy, migraines, etc.) or leave for other countries. If funding does not increase in Canada, the opportunity to recruit clinicians who are interested in movement disorders could soon become even more challenging.



#### CONCLUSION

#### **KEY PRIORITIES**

During the Parkinson Canada Roundtable Series, members of the Canadian Parkinson's community spoke honestly about their current challenges and were both enthusiastic and hopeful that their shared insights will move towards meaningful action.

Upon concluding the roundtable series and after months of engaging with people living with Parkinson's, care partners, healthcare professionals, and other Parkinson's community organizations from across the country, we have gathered insights and have identified the following key priorities for improving the quality of life for people living with Parkinson's in Canada.

- Gaps have been identified in the support of development and promotion of Parkinson's curriculum and awareness for family physicians and allied healthcare professionals. Work needs to be done to address these gaps and provide additional training and knowledge transfer to qualified healthcare providers, which will allow for earlier diagnosis and treatment of Parkinson's.
- Systemic issues exist within healthcare across Canada, which means people living with Parkinson's are underserved given the limited number of Parkinson's Nurse Specialists and Movement Disorder Specialists. Systemic issues and barriers throughout the healthcare system need to be examined to determine what steps can be taken to increase the number of healthcare providers available to support people with Parkinson's.
- Equitable access to care and treatments for all Canadians living with Parkinson's is essential. This includes exploring the availability and wait times for life-changing treatments and access to Health Canada approved medications.

These priorities will help provide a roadmap to the organization in developing our future advocacy work in support of Canadians living with Parkinson's.

#### **NEXT STEPS**

The roundtable series was an opportunity to hear from the Parkinson's community and get direction on advocacy needs to help inform the development of an advocacy strategy for the organization. These roundtables and reports are the first step in this process and will be the foundation of future advocacy efforts.

The next step is the development of a Parkinson Canada Advocacy Strategy based on these key priorities, which will outline how the organization, along with all Canadians, can play a role in advocating for those living with Parkinson's.

We will continue to build relationships with key stakeholders and government officials to raise awareness about the gaps that currently exist in Parkinson's healthcare. In addition, we will continue to collaborate with community organizations across the country to address these advocacy issues and work towards our mission of transforming the lives of people living with Parkinson's in Canada.



#### **ACKNOWLEDGEMENTS**

### PARKINSON ADVISORY COUNCIL (PAC)

Parkinson Canada is grateful to Parkinson Advisory Council members Bob Kuhn and Joe van Koeverden, who participated in all roundtables.

#### COMMUNITY ORGANIZATION COLLABORATION

Parkinson Canada recognizes we are stronger together and appreciate the support for the roundtables from the following organizations:

Parkinson Association of Alberta

Parkinson Society British Columbia

Parkinson Society Newfoundland & Labrador

Parkinson Society Southwestern Ontario

Parkinson Quebec

U-Turn Parkinson's

#### ABOUT PARKINSON CANADA

People with Parkinson's are at the centre of everything we do. Our mission is to transform the lives of people living with Parkinson's.

Parkinson Canada funds critical research, provides information and support, increases awareness and advocates for improved healthcare outcomes for people living with Parkinson's across Canada.

https://www.parkinson.ca/



#### **APPENDIX**

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